"THE LONELINESS OF HIV-INFECTED LOW-INCOME MOTHERS: IMPLICATIONS FOR HEALTH WORKERS"

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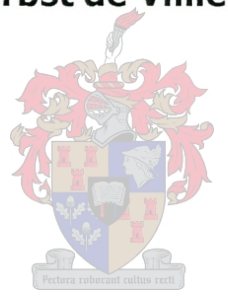

Assignment presented in partial fulfillment of the requirements for the degree of Master of Arts (Clinical Psychology) at the University of Stellenbosch

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I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

The loneliness of HIV-infected low-income mothers: Implications for health workers

Summary

In a qualitative study, a convenience sampling technique was used to ensure a study population of eleven HIV-infected low-income women. These participants were all direct referrals from municipal clinics and the provincial hospital. The criteria for participation were HIV sero-positivity and being a mother of a child or children. Semi-structured open-ended individual interviews were conducted, transcribed and then analysed, using grounded theory. Additional data were gained by using a standardised psychological measure, the Revised UCLA Loneliness Scale (RULS). The two main types of loneliness that these women experienced were loneliness of emotional isolation and loneliness of social isolation. These terms can be defined as the absence of a close emotional attachment and lack of support and understanding of intimate others (emotional isolation) and the absence of an accessible and engaging social network and lack of social support and acceptance (social isolation). The most significant causes of loneliness for these women were stigmatisation; fear and/or shame of rejection and victimisation; fear of losing custody or care of their children; fear of losing financial and emotional support; and using secrecy and non-disclosure as main coping strategy for their emotional and physical safety. Experiences of emotional isolation were also provoked or enhanced by the lack of involvement and support from their partners and the partners' denial of the illness and its consequences. Experiences of social isolation were also caused or increased by the general lack of HIV/AIDS information, education and support services. Significantly, it was found that for most of the women the psychological effect of loneliness was primarily a depressed mood as well as using negative coping mechanisms, such as alcohol abuse and further withdrawal from important others. The psychosocial needs of

these women were also significantly similar. Broad guidelines are offered for health workers in assisting/supporting HIV-infected low-income mothers in general, based on the core needs of the women in this study; **to be listened to and heard, understanding and acceptance, and social support.**

Die eensaamheid van MIV-geïnfekteerde lae-inkomste-moeders: Implikasies vir gesondheidswerkers

Opsomming

In 'n kwalitatiewe studie is 'n gerieflikheidsteekproeftegniek gebruik om 'n studiepopulasie van elf MIV-geïnfekteerde lae-inkomste-vroue te verseker. Hierdie deelnemers was almal direkte verwysings van munisipale klinieke en die provinsiale hospitaal. Die kriteria vir deelname was MIV-sero-positiwiteit en moeder wees van 'n kind of kinders. Semigestruktureerde oop individuele onderhoude is gevoer, getranskribeer en toe ontleed deur gegronde teorie te gebruik. Bykomende data is verkry met behulp van 'n gestandaardiseerde psigometriese instrument, die "Revised UCLA Loneliness Scale (RULS)". Die twee hooftipes eensaamheid wat hierdie vroue ervaar het was eensaamheid van emosionele isolasie en eensaamheid van sosiale isolasie. Hierdie terme kan omskryf word as die afwesigheid van 'n nou emosionele band en gebrek aan ondersteuning en begrip van intieme ander (emosionele isolasie) en die afwesigheid van 'n toeganklike en inskakelende sosiale netwerk en gebrek aan sosiale ondersteuning en aanvaarding (sosiale isolasie). Die beduidendste oorsake van eensaamheid vir hierdie vroue was stigmatisasie; vrees en/of skaamte vir verwerping en viktimisasie; vrees vir verlies van voogdyskap of sorg van hul kinders; vrees vir die verlies van finansiële en emosionele ondersteuning; en die gebruik van geheimhouding en nie-openbaarmaking as belangrikste hanteringstrategie vir hul emosionele en fisieke veiligheid. Ervarings van emosionele isolasie is ook uitgelok of versterk deur die gebrek aan betrokkenheid en ondersteuning van hul lewensmaats en die lewensmaats se ontkenning van die siekte en sy gevolge. Ervarings van sosiale isolasie is ook veroorsaak of verhoog deur die algemene gebrek aan inligting, opvoeding en ondersteuningsdienste ten

opsigte van MIV/VIGS. 'n Betekenisvolle bevinding was dat vir die meeste van die vroue die psigologiese effek van eensaamheid primêr 'n depressiewe gemoedstemming was sowel as die gebruik van negatiewe hanteringstrategieë soos alkoholmisbruik en verdere onttrekking van belangrike ander. Die psigososiale behoeftes van hierdie vroue was ook beduidend eenders. Breë riglyne word voorgestel vir gesondheidswerkers wat betref die bystaan/ondersteuning van MIV-geïnfekteerde lae-inkomste-moeders in die algemeen, gebaseer op die kernbehoeftes van die vroue in hierdie studie; **om na geluister en gehoor te word, begrip en aanvaarding, en sosiale ondersteuning.**

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"Loneliness ... is sharpest and most poignant in the individual who has, for one reason or another, found himself standing, without some of his customary defences, a vulnerable, frightened, lonely but real self, sure of rejection in a judgmental world."

Carl Rogers

1. LITERATURE REVIEW

1.1 Introduction

Historically, HIV (Human Immuno-deficiency Virus) and AIDS (Acquired Immuno-deficiency Syndrome) have been viewed and studied primarily as a man's disease (gay men and drug addicts) (Dicks, 1994; Faithfull, 1997; Kaplan, 1995; Land, 1994; Norman & Dumois, 1995; Overall, 1991; Williams, 1995). Since women were considered to be at low risk for contracting the virus, they were excluded from the discussion. This invisibility can be illustrated by the very definition of AIDS, which, until recently, was based on male symptoms, and excluded many gynaecological and other symptoms unique to women (Faithfull, 1997; Norman & Dumois, 1995; Williams, 1995). Women were generally depicted as vectors of virus transmission and not observed as individuals needing medical attention or psychological support.

Despite the growing numbers of women with HIV/AIDS, there is a paucity of research about the physical and psychological consequences of HIV infection for women in general, and mothers in particular. According to Faithfull (1997) and Norman and Dumois (1995), little is known about the process of the disease in women or the most adequate treatment procedures for women with HIV/AIDS, and there are few resources to meet these women's medical and psychosocial needs. Lachman (1991) has emphasised that the HIV/AIDS problem in women and children will no doubt become one of the major challenges to public health, health care and social support systems worldwide.

The joint report of the UN AIDS / World Health Organisation (UNAIDS/WHO) programme issued in June 2000 states that 34.3 million people worldwide are infected with HIV or have AIDS. Of this global figure 33 million are adults, of which women account for 15.7 million, and 1.3 million are children 15 years of age and younger. The report estimated the total number of Africans living with HIV or AIDS to be 25.3 million. An estimated 15 million Africans have died of AIDS, representing more than 75% of those who have died of AIDS-related illnesses worldwide. During 2000, millions of Africans infected in earlier years began falling ill, and 2.4 million people died of HIV-related causes, compared with 2.3 million in 1999 (UNAIDS/WHO, 2000). Sub-Saharan Africa, home to just 10% of the world's population, continues to bear the brunt of HIV and AIDS, with more than seventy percent (24.5 million people) of the global total of HIV-positive people. Fifty five percent of the 25.3 million people with HIV or AIDS in Sub-Saharan Africa is women (UNAIDS/WHO, 2000). With a total of 4.2 million infected people, South Africa has the largest number of people living with HIV/AIDS in the world, as well as one of the world's fastest-growing epidemics with close to 1 700 people infected every day (Whiteside & Sunter, 2000; Zuma, 1998).

Statistics show that young heterosexual women are the fastest growing HIV-infected population in South Africa and in the rest of the world (Berkley, Naamara, Okware & Downing, 1991; Dicks, 1994; Kaplan, Marks & Mertens, 1997; Kaplan, 1995; Koppers, 1994; Lachman, 1991; Land, 1994; Luiz, Roetz & Smart, 1995; Norman &Dumois, 1995; Whiteside & Sunter, 2000; Williams, 1995; Zuma, 1998). Already one in four South African women between ages 20 and 29 are infected with the virus (UNAIDS/WHO, 2000). Recent studies suggest that in many African countries, antenatal predictions tend to underestimate the real levels of HIV infection in women. The reason is that infected women progressively become less fertile; the more their HIV infection progresses, the less likely they are to fall pregnant (UNAIDS/WHO, 1999). Thus many HIV-infected women are no longer becoming pregnant and are therefor not showing up at antenatal clinics where blood samples for anonymous HIV

testing are taken. These studies suggest that the antenatal estimates fail to reflect the true extent of HIV infection in the female population as a whole.

Infection rates among young African women are far higher than among young men, with rates for teenage girls in some countries five times higher than for teenage boys. Among young people in their early twenties, the rates were three times higher for women. In Africa, women's peak infection rates occur at earlier ages than those of men. This helps to explain why there are an estimated 12 women living with HIV for every ten African men (UNAIDS/WHO, 2000). Goosen and Klugman (1996) also state that AIDS is three times more common in women than in men. This can be ascribed to the fact that approximately 75% of HIV infected people in the world acquired the disease through heterosexual contact, only 5 to 10% through homosexual transmission, 3 to 5% through blood transfusions, and 5 to 10% through sharing HIV-infected drug injection equipment. In South Africa, approximately 79% of people acquired the disease through heterosexual contact, 13% from mother to baby, 7% through homosexual contact, and 1% through contact with HIV-infected blood (UNAIDS/WHO, 2000). Factors contributing to higher HIV infection in women are the greater efficiency of male-to-female HIV transmission through sex and the younger age at initial infection for women (UNAIDS/WHO, 1999). According to a European study, male-to-female transmission is twice (1.9 times) as efficient as female to male transmission (European Study Group, 1992).

In addition to the physiological reasons, various social, cultural and economic reasons contribute to the high numbers of women contracting HIV/AIDS. Many writers and researchers emphasise that AIDS is increasingly afflicting low-income women who have little economic, political or social power (Chachkes, 1987; Dicks, 1994; Gillman & Newman, 1996; Hackl, Somlai, Kelly & Kalichman, 1997; Kaplan et al., 1997; Land, 1994; Williams, 1995). According to Hackl et al. (1997), the stressors on HIV-infected women with few financial resources are often compounded by the multidimensional responsibilities of being the family's primary caregiver. The impact of HIV/AIDS on

these women has been termed 'triple jeopardy'. Tallis (1998) explains that 'triple jeopardy' focuses on the key roles that women have in society and analyses the effect that HIV/AIDS has on these roles. Consequently, HIV and AIDS affect women as individuals, mothers, and caregivers (Tallis, 1998).

1.2 The psychosocial effects of HIV and AIDS on women

AIDS as a life-threatening and highly stigmatised disease not only threatens physical and mental health but every aspect of a woman's existence, from primary relationships to economic survival (Hackl, Somlai, Kelly & Kalichman, 1997; Lachman, 1991; Stein, Steinberg, Allwood, Karstaed & Brouard, 1994; Walker, Pomeroy, McNeil & Franklin, 1996). Society's negative attitudes towards HIV-positive persons, which hold them responsible for their disease, have been well documented in the literature (Balmer, 1991; Dicks, 1994; Ewing, 1994; Gillman & Newman, 1996; Kiemle, 1994; Lachman, 1991; Land, 1994; Leask, Elford, Bor, Miller & Johnson, 1997; Macks, 1987; Mc Ginn, 1996; Newmark & Taylor, 1987; Schurink, 1990; Sewpaul & Mahlalela, 1998; Walker et al., 1996; Zlotnik, 1987). Recent research has argued that prejudice towards persons living with HIV/AIDS is a result of both fear of infection, suffering and death and the association of the infection with marginal populations, such as people with sexual promiscuous behaviour and people living in disadvantaged areas (Dukes & Denny, 1995). Although HIV is an infectious agent with specific modes of transmission, it has often been misinterpreted as a casual-contact virus. According to Dukes and Denny (1995), this misconception has contributed to negative narrative responses, hysteria and social distance from persons living with HIV.

Consequently, the disclosure of an HIV diagnosis raises issues around stigma, discrimination, isolation, alienation, reduction in self-esteem and various conflicts and losses arising at different stages of the disease (Dean, 1995; Gillman & Newman, 1996; Hackl et al., 1997; Kelly & Lawrence, 1998; Kiemle, 1994; Land, 1994). According to Muzzin (quoted in Pequegnat & Stover, 1999), the stigma associated

with AIDS may result in social isolation (both community- and self-imposed), as has been found in the case of cancer survivors and their families, which can have a negative effect on treatment adherence and health status.

Studies conducted by Chinkanda (1990), Faithfull (1997), Gillman and Newman (1996) and Hackl et al. (1997) found that guilt, shame and fear of rejection and potential loss of self-esteem, due to social stigma, were some of the most important emotions that a woman with AIDS has to deal with. The participants in the study conducted by Sandstrom (1993), revealed painful feelings such as grief, guilt, and death anxiety; which often diminished their desire and ability to participate in social interactions. According to Dean (1995), Kelly and Lawrence (1998) and Tiba (1990), additional emotional reactions to the disease that require attention are denial of the illness, stress, anger and grief. Hackl et al. (1997) found in their study on women with HIV infection that the women's concerns about death, dying and despair created intense feelings of hopelessness and isolation, fear of suffering during the dying process and suicidal thoughts.

In the literature, depression and anxiety are described as the two most common psychological reactions following a diagnosis of AIDS or HIV (Faithfull, 1997; Gillman & Newman, 1996; Jue, 1994; Kaplan et al., 1997; Kelly & Lawrence, 1988; Kiemle, 1994; Linn, Poku, Cain, Holzapfel & Crawford, 1995, Schwartz, 1987; Zlotnik, 1987). Isolation and loneliness associated with mourning, a depressive mood and anxiety usually result when the diagnosed person withdraws from others out of fear of rejection, or when existing social support networks withdraw from the person following her diagnosis. Luiz et al. (1995), Macks (1987), Schurink (1990), Schwartz (1987) and Taylor (1991) describe the recognised stages of a terminal illness syndrome, or stages of anticipatory grief as identified by Kübler-Ross, as follows: denial, anger, bargaining, depression and acceptance. These stages are intensified and complicated by a lack of social support, social isolation and stigmatisation associated with an HIV/AIDS diagnosis (Doka, 1990). According to Faithfull (1997),

the grief observed in HIV-infected persons compares well with a typically pathological or abnormal grief reaction, which can enhance a depressive mood, anxiety and loneliness. Loneliness most probably exacerbates these women's emotional desolation and pain. The widespread prevalence of loneliness among people with life-threatening diseases such as AIDS and the negative social consequences it has, indicate that further research is needed on ways to detect and support those who are lonely as a result of such a diagnosis.

1.3 Loneliness

1.3.1 Defining loneliness

Even though research on loneliness has increased in the past two decades, no consensus has been reached on the core meaning of the construct. Various definitions have, however, been offered by social scientists (Demir & Fisiloglu, 1999). According to Peplau and Perlman (1982), there appear to be three very important points of agreement in the way that loneliness is viewed. First, loneliness results from deficiencies in a person's social relationships. Second, loneliness is a subjective experience; it is not synonymous with objective social isolation. Third, the experience of loneliness is unpleasant and distressing. Peplau and Perlman (1982) define loneliness as follows: "Loneliness is the unpleasant experience that occurs when a person's network of social relations is deficient in some way, either quantitatively or qualitatively" (p. 4).

According to College (1995), one of the most comprehensive definitions of loneliness is that of Rook:

> Loneliness is defined as an enduring condition of emotional distress that arises when a person feels estranged from, misunderstood, or rejected by others and / or lacks appropriate social partners for desired activities, particularly activities

> that provide a sense of social integration and opportunities for emotional intimacy. (p. 827)

Parallel to numerous definitions of loneliness, one can also distinguish between different classifications. Young (quoted in Peplau & Perlman, 1982), from a behavioural point of view, identifies insufficient social reinforcement as the main deficiency experienced by lonely people. In his approach social relations are viewed as providing a particular type of reinforcement. Periods of isolation deprive a person of this type of reinforcement and consequently result in the experience of loneliness. Weiss, the leading spokesperson for an interactionist approach to loneliness, states that loneliness is caused not by being alone but by being without some definite needed and meaningful relationship, or set of relationships, or connectedness with a coherent and supportive community (Peplau & Perlman, 1982; Weiss, 1973). Weiss (1973) emphasises that loneliness arises when one's social interactions are deficient in supplying crucial social requirements such as attachment, guidance and a sense of worth. According to him there are two types of loneliness, emotional isolation and social isolation. The first is produced by the absence of a close emotional attachment or a lack of intimate others, and the second by the absence of an accessible and engaging social and community network. Loneliness arising from social isolation is the situation of the individual without sufficient links to and support from the surrounding community. According to Weiss (1973), anything that leads to loss of contact with those who share one's concerns, like social stigmatisation and prejudice, may give rise to social isolation. Dukes and Denny (1995) emphasise that a fatal illness such as AIDS, which is accompanied by much suffering, creates greater perceived danger of contact and increases social prejudice and distance.

Perlman (1989) emphasises that Weiss's distinction between social and emotional loneliness, based on the nature of the social deficit (intimate or community ties), is clearly one of the most influential in the literature. According to Perlman (1989), it is part of a general search for identifying types of loneliness, as other writers have

distinguished chronic from temporary loneliness, and negative versus positive forms of aloneness. Still others have discussed such types of loneliness as self-estrangement or existential loneliness (Sadler & Johnson quoted in Perlman, 1989). Perlman (1989) states that existential loneliness may be more tied to the lack of religion or meaning in life than to a lack of interpersonal bonds. Perlman (1989) further suggests that virtually all loneliness involves negative emotions, and that the positive experience of aloneness should be called solitude.

1.3.2 Loneliness as multidimensional construct

Although Jones and Moore (quoted in Rokach, 1997) suggest that the majority of researchers conceptualise loneliness as a singular and unidimensional construct, Rokach and Brock's research indicates that loneliness is a multidimensional experience, which has certain cognitive, emotional and behavioural manifestations. According to Rokach (1997), it is unlikely that the combination of such manifestations and the experience of loneliness are the same for any two people. In the same way, beliefs about the causes of loneliness are varied and seem to correspond to the cognitive, emotional and behavioural components of the self-reported experience of loneliness. Marangoni and Ickes (quoted in Rokach, 1997) describe the subjectivity of the experience of loneliness as "a relatively ambiguous internal state lacking a single, unique set of defining cognitions, emotions or behaviour (p. 1068)".

Rokach and Brock's research into the multidimensionality of loneliness reveal five factors which comprise the experience of loneliness, as can be seen in Figure 1 (p. 9): 1) Emotional distress (accounted for 19% of the variance) describes the intense pain, inner turmoil, hopelessness, and feelings of emptiness associated with loneliness; 2) Social inadequacy and alienation (7% of the variance) describe the social alienation and concomitant self-generated social detachment; 3) Growth and discovery (4% of the variance) describe the positive, growth-enhancing and enriching aspects of the loneliness experience and the increased feelings of inner strength which follow; 4)

Interpersonal isolation (3%) describes feelings of alienation, abandonment, and rejection which were reported as relating to a general lack of close relationships or absence of a primary romantic relationship; 5) Self-alienation (3%) describes detachment from oneself characterised by numbness, immobilisation and denial (Rokach & Brock, 1997, p. 292 - 293). Moustakes and Mayer-Gaev's (in Rokach & Brock, 1998) description of loneliness focuses on this last factor: "a feeling of inner void, a detachment from one's self, and an alienation from one's core identity" (p. 111). According to Rokach (1997), there are similarities between Weiss's unidimensional description of loneliness and the above multidimensional model. The loneliness of emotional isolation is similar to emotional distress (Factor 1) and interpersonal isolation (Factor 4), which is linked to a sense of utter loneliness and feelings of abandonment and rejection, while the loneliness of social isolation is reflected in Factor 2, social inadequacy and alienation.

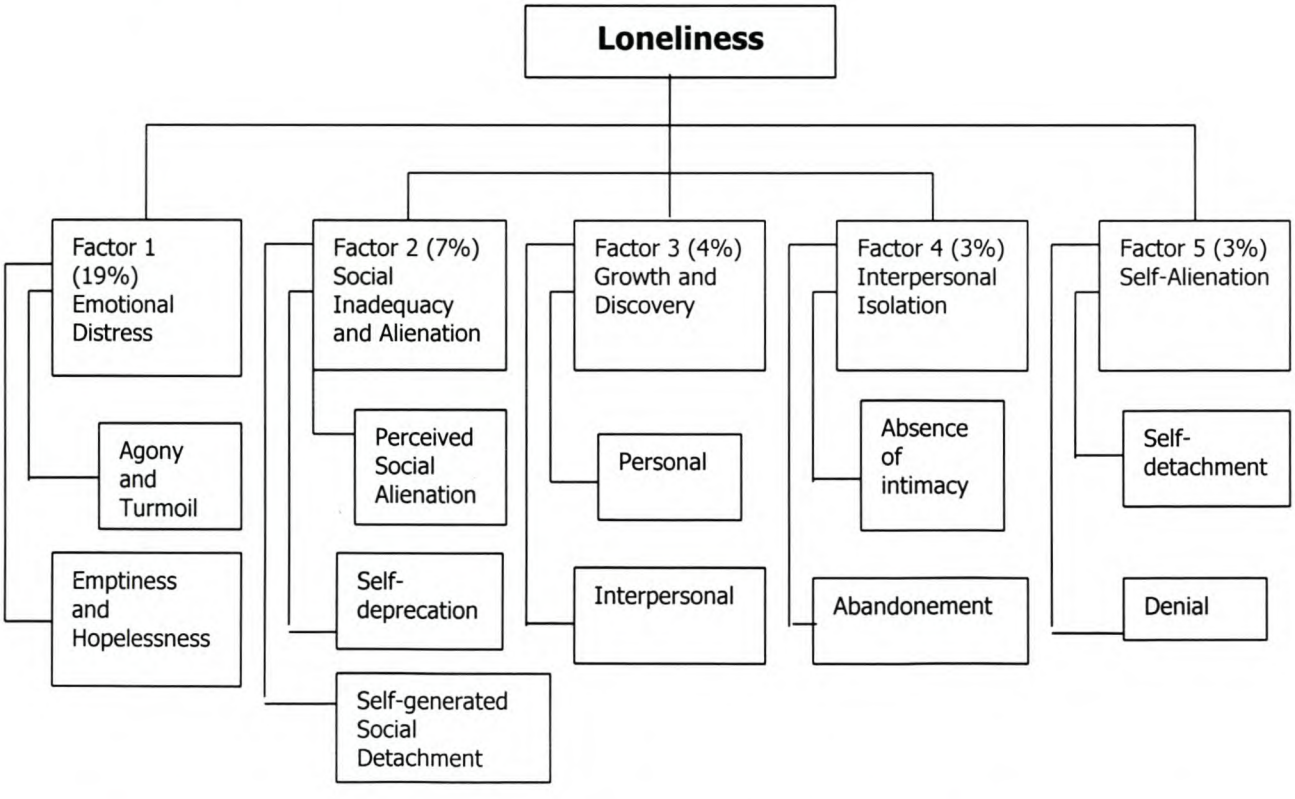

Figure 1. Multidimensional model of loneliness (Rokach & Brock, 1977, p. 287)

1.3.3 Causes of loneliness

On the basis of their research, Rokach and Brock (quoted in Rokach, 1997) propose a general model for the perceived causes of loneliness which consists of five factors: 1) Personal inadequacies (17% of the variance), which includes items that describe enduring personal characteristics or previous aversive experiences associated with low self-esteem, mistrust, fear of intimacy and feeling socially ill at ease; 2) Developmental deficits (5%) describes possible developmental and familial antecedents of adult loneliness such as growing up in an inadequate or dysfunctional home that would be characterised by emotionally distanced or rejecting parents or psychological or physical abuse; 3) Unfulfilling intimate relationships (4%) describe the effect of disappointing, hurtful or emotionally abusive intimate relationships or friendships on the development of loneliness; 4) Relocation and significant separations (4%) describe the changes and often loss of important relationships that occur as a consequence of mobility, relocation or death; 5) Social marginality (3%) describes the social rejection and distancing which criminals, the unemployed and chronically ill persons commonly experience (p. 1068).

Perlman and Peplau (quoted in Perlman, 1988) have formulated a discrepancy model of loneliness (see Figure 2, p. 11). They find it helpful to distinguish between predisposing factors that make people vulnerable to loneliness and precipitating events that trigger the onset of loneliness. According to Perlman and Peplau (in Perlman, 1988), predisposing factors can include characteristics of the person (e.g. shyness, lack of social skills), characteristics of the situation (e.g. competitive interaction, social isolation) and general cultural values (e.g. individualism). Precipitating events are factors such as the break-up of a love relationship, moving to a new community or being diagnosed with a terminal illness, that in turn change a person's social life in some significant way. Perlman and Peplau (quoted in Perlman, 1988) state that these events create a mismatch between the person's actual social

relations and the person's needs or desires. Therefore a change in one of these two factors without a corresponding change in the other can produce loneliness.

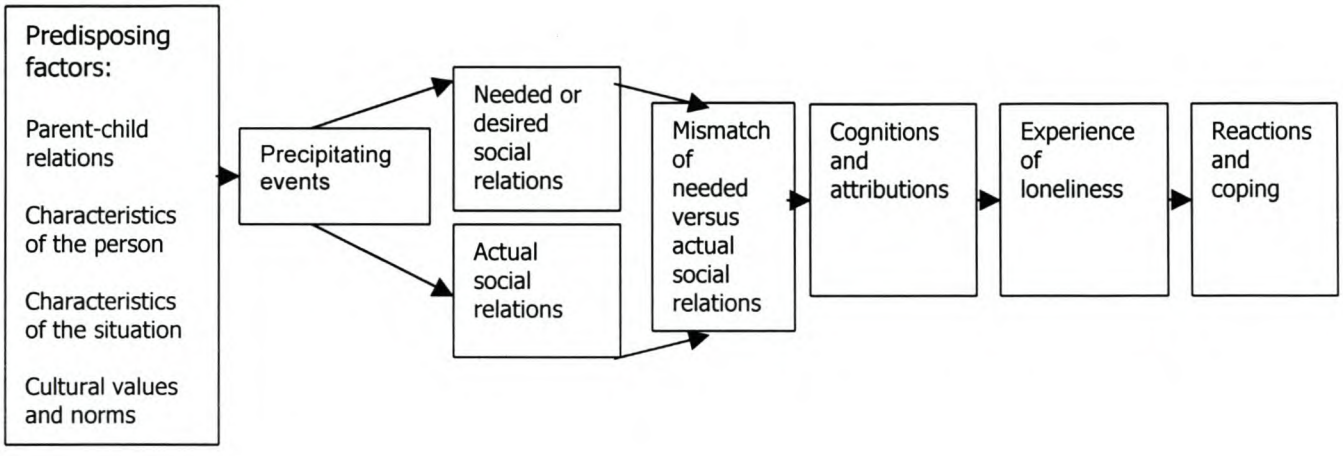

Figure 2. Discrepancy model of loneliness by Perlman and Peplau (in Perlman, 1988, p. 194)

1.3.4 The meaning hypothesis

Stuewe-Portnoff (1988) proposes a conceptual framework that exposes an essential core common to all experiences of loneliness, namely the experience of isolation, disorientation, or lostness within a dimensional domain of meaning. "Life as a human being entails coexistence within two interpenetrating phenomenal domains, one a physical universe of things, the other a symbolic universe of meanings" (Stuewe-Portnoff, 1988, p. 547). According to him our physical domain is generally more stable and secure than the web we have each constructed of interrelated meanings and functional relations, where a person's real aspirations, joys and sorrows, apprehensions and hopes, failures and fulfilments reside. The lack or disruption of romantic attachments, familial relationships or friendships typically precipitates episodes of loneliness. Schmidt and Sermat (quoted in Stuewe-Portnoff, 1988)

confirm this triad and add a fourth component, namely deficits in relationships with larger groups or the community.

Stuewe-Portnoff's (1988) meaning hypothesis suggests two separable dynamics operative in such situations of estrangement from relationships of mutual caring. On the one hand a person has lost someone who is meaningful to him or her, an experience commonly called "missing", but the same situation has estranged the person from someone to whom he or she is meaningful. Stuewe-Portnoff (1988) explains the latter by moving to the domain of physical space; the location of an object cannot be specified without reference to another object. He emphasises that a person's orientation within the symbolic universe requires the collaboration of another being to whom that person has meaning. Weiss also believes that the bases of loneliness are clearly linked to the lack of meaning or connectedness with another being: "Loneliness appears always to be a response to the absence of some particular type of relationship...in many instances it is a response to the absence of the provisions of a close, indeed, intimate, attachment" (quoted in Rokach, 1997, p. 1069).

Another precursor of loneliness, less commonly reported than lack or disruption of relationships of mutual caring, is facing a personal crisis (Curtrona, 1982 and Portnoff, 1976 quoted in Stuewe-Portnoff, 1988). For the latter to be consistent with the meaning hypothesis, a link between facing a crisis and dislocation within one's domain of meaning is required. According to Stuewe-Portnoff (1988), the link would be the same element active in other situations that precipitate loneliness, namely interpersonal estrangement. He clarifies this as follows:

> Facing a common problem is conducive to group cohesiveness, dealing with one not shared by others is alienating. My experience of 'being with' is not simply a matter of physical proximity, but also of the extent to which the world means the same thing to others that it means to me. Thus, when a problem you don't recognise, or issues that are of no consequence to you pervade my

> world, a gulf opens between us. When the meaning domain you inhabit differs in fundamental ways from mine, I experience us as existing in different worlds. (Stuewe-Portnoff, 1988, p.548)

Thus a person diagnosed with HIV or AIDS will not easily experience common group cohesiveness or be able to share emotions and thoughts regarding the diagnosis with important others, owing to stigmatisation and fear of rejection. This interpersonal estrangement can precipitate loneliness that can lead to the development of physical, psychological and behavioural problems and conditions such as depression and anxiety (Rokach & Brock, 1998).

1.3.5 Psychological consequences of loneliness

Primary goals of research studies have been to identify the causes and consequences of loneliness. Research results on loneliness have generally shown a positive connection between the subjective experience of loneliness and impaired mental health, including neuroticism, low self-esteem, depression, anxiety, psychosomatic concerns, interpersonal hostility / aggression and paranoia (Jackson & Cochran, 1990; Rokach & Brock, 1998; Rokach, 1996). According to Demir and Fisiloglu (1999) health and psychological problems, substance abuse, suicide and depression are the most frequently studied correlates of loneliness. The West et al. review of studies on loneliness (quoted in Demir & Fisiloglu, 1999), shows that child abuse and neglect, bereavement, physical health problems, and stress are other possible correlates of loneliness. Loneliness is furthermore associated with psychological problems such as eating disorders (Nurmi, Toivonen, Salmela-Aro & Eronen, 1997) and alcohol abuse and dependency (College, 1995). It was also concluded in two carefully controlled studies conducted by Berkman and Syme and House, Robbins and Metzner (quoted in Rokach et al., 1998) that earlier death has been linked to social isolation.

Relationships between depression and loneliness have particularly been discussed in the literature (Bradburn, Bragg, Young, & Schmidt quoted in Peplau & Perlman, 1982; Jackson et al., 1990). Results of a study conducted by Jackson and Cochran (1990) show significant relationships, for both women and men, between depression, interpersonal sensitivity or low self-esteem, and loneliness. According to the researchers, these findings help to clarify relationships between psychological distress and loneliness. Rubenstein and Shaver (quoted in De Gouveia, 1984) state that depression and self-deprecation are probably best conceptualised as reactions to loneliness. Studies conducted by Numri et al. (1997) show similar results than earlier studies (Peplau & Perlman, 1982), inter alia that low self-esteem is associated with subsequent feelings of loneliness. Numri et al. (1997) give two explanations for this finding:

> First, people with low self-esteem are less successful in initiating meaningful relationships than those with high self-esteem; this inclination is then reflected in their feelings of loneliness. Second, feelings of loneliness are related to overall negative attitudes towards social reality and these attitudes are also reflected in the ways people view themselves. (p. 774)

Russel, Cutrona, Rose and Yurko (quoted in Jackson & Cochran, 1990) found that depression is more strongly associated with emotional loneliness, whereas anxiety is related to social isolation. This link between emotional impairment and loneliness is most comprehensible when one considers associations between loneliness and low self-esteem and / or depression, both of which are firmly related to perceptions of loss or inadequacy (Jackson & Cochran, 1990).

Peplau and Perlman (1982) propose that the prototype of a lonely person is itself nested within the prototype of a depressed person. That is, the major traits of a lonely person are a subset of those of a depressed person. This relationship implies that it is more probable for a lonely person to complain of feeling depressed than it is for a depressed person to complain of feeling lonely.

According to Young (quoted in Peplau & Perlman, 1982), situational or transitional loneliness involves individuals who had satisfying relationships until they were confronted either with a specific crisis such as death or divorce, or with a predictable developmental change. As a result of the transition, they feel lonely frequently and for substantial periods of time. Young further states that individuals may initially fall into the situational category and, if they have not adjusted to the change within two years, they would then be recategorised as chronically lonely (quoted in Peplau & Perlman, 1982). The results of a study conducted by DeBerard and Kleinknecht (1995) suggest that both intensity and duration of loneliness are predictive of stress symptomatology, such as depression, anxiety, anger, and somatic complaints; however, duration of loneliness appears to be a significantly better predictor than intensity of loneliness. Friedman and Katz (quoted in De Gouveia, 1984) suggest that prolonged or chronic loneliness or repeated rejection leads to self-blame and finally to depression. According to Rokach and Brock (1998), a lonely person is generally regarded as undesirable. As a result of the stigma attached to being lonely, most lonely people do not reveal, let alone discuss, their actual thoughts and feelings while they are undergoing the experience. This may lead to ineffective coping mechanisms, such as substance abuse. Consequently, a person with HIV/AIDS could experience severe emotional distress and psychological symptoms as discussed above, because of the stigmatisation attached to both the disease and their state of loneliness.

According to Stuewe-Portnoff (1988), whether or not loneliness is precipitated by having a problem that others seemingly do not share, the condition generally constitutes such a problem. The communality enjoyed by other people presents a painful contrariety to the lonely person's isolation. On the other hand, Stuewe-Portnoff (1988) states that to interact with the lonely person in ways that are inharmonious with his or her inner life, amounts to exchanging alienation from others for alienation from the self. Thus interacting without sharing inner emotions and experiences may lead to a shallow or superficial existence.

1.3.6 Terminal illness as personal crisis, and loneliness

Yalom (1995), a well-known group therapist who has lead many groups of patients who all had some advanced form of cancer, states the following: "I was repeatedly struck by the realization that, in the face of death, we dread not so much nonbeing or nothingness but the accompanying utter loneliness" (p. 21). According to him, dying patients may often be haunted by interpersonal concerns of being abandoned, even shunned, by the world of the living.

Derlega and Margulis (quoted in Peplau & Perlman, 1982) illustrate how patients with terminal conditions face terrible uncertainties associated with their illness. Patients who seek to clarify their feelings may become isolated and lonely, because of their own and others' inability to talk about the illness. They may fear that others will reject them if they discuss their illness. According to Derlega and Margulis (quoted in Peplau & Perlman, 1982) health professionals may also avoid talking with patients about their illness on account of their own anxieties, which in turn makes it even more difficult for patients to talk about their problems. The absence of an appropriate person with whom to share their emotions and who will protect their intimate disclosures may lead to interpersonal estrangement and loneliness. Torres (quoted in Sherr, 1995) compared the Kübler-Ross grief model in AIDS and cancer patients and found that people with AIDS become significantly more depressed and lonely than those with cancer. People with AIDS needed to talk about their losses while the cancer respondents analysed their grief. According to Torres (quoted in Sherr, 1995) people with AIDS tend to indicate a greater need for family and peer support, but because of stigmatisation and fear of rejection this need is rarely satisfied. Consequently, this may lead to further emotional and social isolation.

1.4 The need for research on AIDS, low-income women and loneliness

Psychological distress such as loneliness has been identified as particularly troublesome for certain groups such as single mothers with low income (Rokach, 1997). According to Kneisl (quoted in Gillman & Newman, 1996), women with HIV infection must cope with sources of stress and anxiety different from those of infected men: "...women generally have fewer economic resources, more role responsibilities (caring for family members, children and generating income), and fewer social and community supports than do men" (p. 132). Williams (1995) states that many low-income women with HIV are socially isolated from support services by factors such as unemployment, being single mothers, lack of convenient transportation and substance abuse. In many instances AIDS is only one crisis among many that low-income women must deal with. According to Hackl et al. (1997), insufficient knowledge exists about the special needs and concerns of HIV-infected women, with regard to their health care, children, partners, financial status and sense of future.

The importance and need for in-depth and systematic research on the psychosocial concerns, functioning and needs of people in general with HIV or AIDS are strongly emphasised in the literature (Campbell & Williams, 1996; Dicks, 1994; Linn et al., 1995; Littrell, 1996; Luiz et al., 1995; Schurink, 1990; Williams, 1995). According to Campbell and Williams (1996), such information would provide the baseline for interventions and focus on providing economic, social and psychological support for the most severely affected communities and empowerment programmes for groups at greatest risk, such as low-income women.

In South Africa, limited research has been done on the psychological distress of South African women / mothers who are HIV infected. No research focusing on loneliness in relation to an HIV or AIDS diagnosis has been reported in the literature. Research on HIV/AIDS in South Africa mainly focuses on awareness, prevention and attitudes towards AIDS in general. Therefore a definite need exists for local research to focus

on the psychological concerns and distress (such as loneliness), as well as on the functioning and coping, of women with HIV/AIDS. Because low-income women are traditionally the most marginalised and oppressed sector of our society and are now facing the added burden and devastating effects of HIV/AIDS, they should be the prime target and study population for planning intervention and support strategies.

The specific focus of the present research paper is on emotional and social isolation, as defined by Weiss (1973), for the reason that these experiences of loneliness are very common and relevant psychological concerns and causes of distress for HIV-infected low-income mothers. During grounded theory analysis of the data obtained in the present study, loneliness also emerged as the most prominent catergory of concern. Emotional and social isolation are not only major stressors, but the absence of adequate psychosocial support, owing to inter alia stigmatisation and insufficient health care and counselling services, also means the absence of very important coping mechanisms for these mothers. In addition, the research paper explores the mental health needs of these mothers that emanate from these concerns, which may bring forth relevant information that could be utilised by local health workers.

2. RESEARCH METHODOLOGY

In social constructionist theory, it is argued that reality does not exist, but is continually constructed by people in interaction with each other (Gonzalez, Biever & Gardner, 1994). In other words, the meaning of events in the world is not inevitable or natural, but is rather constructed by social actors, acting and interacting in the social world. Following social constructionist theory it can then be argued that the meaning of AIDS and HIV infection can be different for different women, but that the meaning of the illness and the accompanying losses and needs will always be shaped by the social context within which the woman is functioning. According to Sewpaul and Mahlalela (1998), the women in their study needed varying amounts of time to

relate to others and disclose their HIV status. The way in which the family and community behave and react establishes the context in which a woman with AIDS experiences the processes of her illness. According to Chachkes (1987), some families accept the situation and find ways to meet the emotional and concrete needs of HIV-positive women while others remain too overwhelmed and overburdened to provide sufficient care and support. In understanding the emotional impact of AIDS and HIV infection on women, it seems essential to conduct research on how individual women experience psychological losses and needs in the social contexts within which they are functioning.

The research objectives of the present study are therefore formulated within the framework of a qualitative methodology (Riessman, 1994; Schwandt, 1997). Qualitative research enhances the study and understanding of participants' perspectives and personal experiences within their specific social contexts (Kvale, 1983; Mc Ginn, 1996). The aim of the research project is to observe, analyse and describe phenomena, rather than to generalise on the findings emanating from the data. Therefore semi-structured, open-ended, in-depth interviews were used to gather information. Complementary or additional data were gained by using a standardized psychological measure, the Revised UCLA Loneliness Scale (RULS) (Fischer &Corcoran, 1994).

2.1 Participants

A convenience sampling technique was used to ensure a study population of eleven women. Criteria for participants were a) HIV sero-positivity; b) being a mother of a child or children. The eleven participants were all Coloured women who spoke Afrikaans as their first language. All participants were direct referrals from municipal clinics and the Provincial Hospital in Stellenbosch, Winelands Region, to the AIDS counsellors at the Stellenbosch Hospice for information, counselling and support. The researcher was an AIDS counsellor for the Department of Health at the Provincial

Hospital and Stellenbosch Hospice during this time. All the participants were diagnosed HIV-sero-positive through an AIDS-related illness or infection, or an antenatal or postnatal check-up.

2.2 Procedure

The procedure and objectives of the present study were thoroughly explained to the participants by the researcher and each participant was required to sign an informed consent form that was compiled in Afrikaans, their first language (see Addendum A, p. 72). The researcher herself conducted informal interviews at the local clinics and Provincial Hospital at times that were convenient for the participants. These interviews took approximately two to three hours to complete. The researcher conducted and managed the interviews in an informal, non-directive way to maintain spontaneity and rapport with the participants. Privacy, confidentiality and an empathic-sensitive attitude were of the utmost importance throughout the interviewing process, which contributed to a more open, informal and trusting relationship between the participant and the researcher. The interview consisted of three parts. In the sociodemographic and health questionaire close-ended questons were asked while the section dealing with psychosocial issues assumed the form of an unstructured open-ended interview (see Addendum B1, p. 74). A standardised psychological measure, the Revised UCLA Loneliness Scale (RULS) (see Addendum C1, p. 80), was also administered. Interviews were conducted in Afrikaans, which was the first language of the participants. Consequently both of the measures were translated from English to Afrikaans (see Addendum B2, p. 77, & Addendum C2, p. 81). This gave the participants the freedom to express their own rich stories in their own language, which reflects their individual and unique understanding constructed within their particular contexts. A professional translator interpreted excerpts from the interviews, which are used in this research paper, from Afrikaans into English.

2.3 Measures

Both qualitative and quantitative measures were used in the present study. The interview schedule, as qualitative measure, was developed after consulting the relevant literature on women's issues and AIDS (Hackl et al., 1997; Kaplan et al., 1997), as well as local experts in the field. Every participant was presented with the same set of questions in a pre-ordered sequence. A selection of close-ended questions were used to gather specific socio-demographic information such as age, marital status, education, income, dependants and education, and health-related information such as risk factors for HIV, time since HIV diagnosis, current HIV status and current HIV status of children. Respondents were asked about psychosocial issues in a semi-structured open-ended interview, where questions were asked about specific behaviours, experiences, thoughts and feelings that related to living with a positive HIV diagnosis. Questions focused on response to diagnosis, disclosure, intimacy and support, affect, coping and future concerns and plans. The questions were designed to inquire how the women themselves define and understand their experiences.

The Revised UCLA Loneliness Scale (RULS) was used as standardised psychological measure (Fischer & Corcoran, 1994). The RULS is a twenty-item scale designed to measure respondents' general perceptions of loneliness due to a deficiency in interpersonal ties (Kaplan et al., 1997). Although the scale has not been validated for the specific population of the present study, it has been used in a number of studies that show loneliness as an everyday and distressing problem for many people (Fischer et al., 1994; Peplau et al., 1982). According to Peplau and Perlman (1982), significant relationships were also found between loneliness scores and feeling abandoned, depressed, empty, hopeless, isolated and self-enclosed and with not feeling sociable or satisfied. It has been well documented in the preceding literature that people infected with HIV/AIDS, as a terminal disease, experience high levels of

stigmatisation, anxiety and depression, which most probably contribute to loneliness and isolation.

2.4 Data management and analysis

Grounded theory was applied within the framework of qualitative research. Interviews were audio taped, transcribed and coded by the researcher according to grounded theory protocol. In grounded theory research, actual data collection and transcription are not regarded as processes that are totally disconnected from data analysis, but rather as the first major analytic stage of the research which consists of the coding of the data (Charmaz, 1995). Charmaz stated, "The grounded theorist's simultaneous involvement in data-gathering and analysis is explicitly aimed towards developing theory" (1995, p.32).

In the present study, line-by-line coding was used to label each line of data and to create a wide range of 'initial codes'. According to Charmaz (1995), the purpose of line-by-line coding is to make the researcher keep close to her data and simultaneously think about the material in new ways. It subsequently helps the researcher to gain sufficient distance from her own, and the participants', taken-for-granted assumptions about the material, so that it can be viewed in a new light. A list was compiled of themes that frequently appeared during initial coding (see Addendum D, p. 83). The list of 22 codes was then used in a second round of focused coding, during which all the interviews were coded again in a more workable and purposeful coding process. According to Charmaz (1995), focused coding is less open-ended and more directed, selective and conceptual than line-by-line coding, and permits the researcher to create and to test different categories for capturing data. Charmaz (1995) further states that categories may be in vivo codes that are taken directly from the respondents' discourse or they may represent the researcher's theoretical or substantive definition of what is happening in the data (p.41). In the present study both of these methods were used to analyse the data.

Categories were adapted and changed, focusing on the category that emerged most prominantly during data analysis, namely loneliness. The researcher attempted to build and to clarify the main category by examining all the data relating to it and by identifying the variations within it and between other categories. Therefore new coding categories were formed which serve as the basis for the discussion of the results that follow. The full results of this study will be written up in a subsequent research paper entitled, "The Psychological Concerns of HIV-infected Low-income Mothers in the Winelands Region".

Socio-demographic and health-related data were pre-coded in specific categories as presented in this research paper. The standardised psychological measure (RULS) was manually scored and analysed by the researcher.

2.5 Consultation and ethical considerations

Each participant signed an informed consent form, after the researcher had thoroughly explained the objectives of the present study as well as the research procedure and process. Consultations with all relevant parties were conducted during the research process, to ensure that the research objectives were conveyed and all persons concerned could benefit from the study. Participants were referred for psychological support, counselling or other social aid, if the need was identified during the interviews.

3. BIOGRAPHICAL INFORMATION

As can be seen in Table 1 (p.24), most of the eleven participants are in their late twenties and early thirties. The youngest, Sonja, is 22 years and the oldest, Sylvie, is 47 years old. As stated in the literature, AIDS has become one of the major causes of death for women of reproductive age and women of the age group 20 to

29 years constitute the largest population of AIDS cases in South Africa (UNAIDS/WHO, 2000).

Table 1

Demographic Details of Women Participants

Code name	Age (in years)	Relationship status	Education	Work status	Household income
1. Ann	32	Married	Grade 7	Housewife Cares for children	R1520
2. Maggie	24	Live-in lover	Grade 7	General worker at brick factory (full week)	R2110
3. Mariana	33	Live-in lover	Grade 6	None	R500
4. Joeyce	26	Live-in lover	Grade 3	Cares for child	R885
5. Hester	26	Live-in lover	Grade 9	Housewife Cares for children	R500
6. Rosy	35	Married	Grade 8	Housewife	R500
7. Elna	28	Live-in lover	Grade 9	Cares for child	R1400
8. Sonja	22	Never married	Grade 9	Cares for child	R700
9. Sylvie	47	Separated from husband	Grade 7	Baker (full week and Sat mornings)	R1600
10. Bertha	28	Never married	Grade 7	Housework	R780
11. Nossie	34	Live-in lover	Grade 9	Housewife	R680

Eight of the participants live with their sexual partners and three live with family members. Most of the eleven participants stated that they are dissatisfied with their living conditions and that they live in 'compromised and difficult circumstances'. Mariana, Hester and Rosy live in small one-roomed shacks with no electricity or water. Maggie, Joeyce and Elna live in one room respectively with their partners and children. These participants rent the rooms from family members and have many complaints about a lack of privacy and family rivalry.

Participants voice their need for better housing as follows:

"As ek net my eie plek kan kry en ek kry nou die onderhoud geld, die siekte se geld, dan kan ek nou vir hom (her partner dying of AIDS) help en so aan"
"If I can just get my own place and I get the disability money, the money for the illness, then I can help him (her partner dying of AIDS) and so on" (Joeyce);

"In my toekoms ook, dit voel vir my ek wil eendag as ek in my eie huis kan woon...Ons gat nou al weer 'n winter nog in die hokkies woon, wat gaan dit nou weer veroorsaak, gaan ek weer so siek raak in die winter in die hokkie"
"In my future also, I feel I'd like to live in my own house someday...We're now going to live in the shacks for another winter, what is that going to cause, will I get so sick again in the winter in the shack" (Hester);

"My grootste begeerte is ek wil net 'n plek van my eie hê, nie by mense agter in 'n yard board nie. Ek wil my eie plekkie hê, 'n flat of 'n ding wil ek hê en op my eie is, ek en my kind"
"My biggest wish is that I just want a place of my own, not to board with people in a backyard. I want my own litlle place, I want a flat or something and to be on my own, me and my child" (Sonja).

Only three of the eleven participants are married. Ann and Rosy live with their husbands, but Sylvie has been separated from her husband for the last two years. Most of the participants finished primary school, but only four succeeded in passing grade nine. The average monthly household income is R1016 and seven of the participants reported household incomes below R1000 per month. In South Africa the poor (classified as the poorest forty per cent of households) are defined as those earning less than R355 per adult per month (Whiteside & Sunter, 2000). Considering that for the present study the average number of adults per household is four, the majority of these households can be classified as poor. Only two of the participants, Maggie and Sylvie, work for an income outside the home. All of the other participants, except for Mariana, do housework and care for their children. Because of Mariana's serious alcohol dependency the local welfare services placed her children in the foster care of her mother. Most of the participants would like to work outside the home, but because of their illness they feel physically and

emotionally tired most of the time. They also have the responsibility to care for their children, and eight of the participants have children who are HIV+ and have related illness symptoms. These children of course need special care and attention.

According to Kaplan (1995), areas with higher rates of HIV and AIDS among women, in various countries, appear to be strongly correlated with social problems, including low income, inadequate or insufficient housing, unemployment and low maternal education. Zuma (1998) also emphasises that inter alia, poverty, illiteracy, poor health services, prostitution and poor women's socio-economic conditions contribute to the spread of the HIV and AIDS epidemic in South Africa. Lachman (1991) states that the health status of women is affected by the interrelationship between behavioural risk, low-income and poor environment, and not by each factor alone. According to Williams (1995), many women with HIV are socially isolated by factors such as unemployment, being single mothers, and lack of convenient transportation, and so are particularly isolated from the health care system. These conditions can further contribute to experiences of loneliness, isolation and a lack of social support.

Table 2 (p.27) shows the number of children each participant has as well as the age category for each child. Of the nine HIV-positive children, eight are younger than six years and one child falls into the age category of six to twelve years. The majority of the women were tested for HIV and AIDS during antenatal visits at their local clinic or shortly after the birth of their only or youngest child, and therefore most of the HIV-positive children are in their toddler years. For all of the participants HIV infection occurred through heterosexual intercourse. The time since diagnosis varies from three months to four years.

Table 2

Details on HIV Diagnosis of the Women and their Children

Code name	Age of child/ren	Number of children HIV+	Time since diagnosis of participant	HIV risk categories
1. Ann	1 (0-5 years) 1 (6-12 years) 1(13-18 years)	1 (0-5 years) 1 (6-12 years)	6 months	Heterosexual intercourse
2. Maggie	1 (0-5 years)	None	9 months	Heterosexual intercourse
3. Mariana	1 (0-5 years) 1 (6-12 years)	1 (0-5 years)	12 months	Heterosexual intercourse
4. Joeyce	1 (0-5 years)	None	3 years 6 months	Heterosexual intercourse
5. Hester	1 (0-5 years) 1 (6-12 years)	1 (0-5 years)	3 years 6 months	Heterosexual intercourse
6. Rosy	1 (0-5 years) 1 (6-12 years) 1 (13-18 years)	1 (0-5 years)	4 years	Heterosexual intercourse
7. Elna	1 (0-5 years)	1 (0-5 years)	1 year 6 months	Heterosexual intercourse
8. Sonja	2 (0-5 years)	1 (0-5 years)	6 months	Heterosexual intercourse
9. Sylvie	2 (6-12 years) 1 (13-18 years) 3 (older than 18 years)	Unsure about 2 youngest	1 year 3 months	Heterosexual intercourse
10. Bertha	1 (0-5 years) 1 (13-18 years)	1 (0-5 years)	3 months	Heterosexual intercourse
11. Nossie	1 (0-5 years)	1 (0-5 years)	12 months	Heterosexual intercourse

4. RESULTS AND DISCUSSION

The larger study yielded many interesting results regarding various psychosocial concerns and mental health needs of HIV-infected mothers. The focus of the current paper is, however, on loneliness as primary psychological concern for low-income mothers with HIV or AIDS, as well as on the mental health needs that emanate from this concern.

4.1 Experiences of loneliness

The discussion of the results of the present study is primarily based on Weiss's (1973) unidimensional explanation and Rokach's (1997) multidimensional model of loneliness. According to Weis (1973), there are two types of loneliness, emotional isolation and social isolation. The first is produced by the absence of a close emotional attachment or a lack of intimate others, and the second by the absence of an accessible and engaging social and community network. When one compares Weiss's unidimensional description of loneliness and Rokach's (1997) multidimensional model, certain similarities can be found. As discussed earlier, the loneliness of emotional isolation is similar to emotional distress (Factor 1 of the multidimensional model) and interpersonal isolation (Factor 4 of the multidimensional model), which is linked to a sense of utter loneliness and feelings of abandonment and rejection. The loneliness of social isolation is reflected in Factor 2 of the multidimensional model, social inadequacy and alienation (see Figure 1, p. 9).

In the current study, experiences of loneliness are revealed through quantitative and qualitative measures. The Revised UCLA Loneliness Scale (RULS) produces a possible range of scores between 20 and 80, with higher scores indicating greater loneliness (Fischer & Corcoran, 1994). The norms used by Fischer and Corcoran (1994) are based on inter alia a study measuring loneliness in a student population in the USA. The mean for students who were not dating is 43.1, which is

significantly different from students who were dating casually (34.0) and those who were romantically involved (32.7). The loneliness scores of the participants in the present study range from 43.0 (the lowest score) to 68.0 (the highest score), with a mean score of 55.0. Thus the participant who is the least lonely of all the participants in the present study, as measured by the RULS, has the same score as students who were not dating and is experiencing much higher levels of loneliness than students who were socialising and intimately involved. According to the norms for the student population, which are not standardised norms for the population of the present study, the mean score of 55.0 and highest score of 68.0 indicate that the participants in the present study most probably experience high levels of loneliness in their daily lives. These findings should be interpreted cautiously, because of the ethnical dissimilarities as well as differences in education levels between the two study populations.

In the qualitative interviews, all the participants clearly describe the drastic effect of an HIV/AIDS diagnosis on their daily functioning, specifically mentioning how their diagnoses led to experiences of loneliness. Some of the participants state their feelings as follow:

"Ek voel net nie meer soos ek gewees het nie, ek was 'n springlewendige mens. Ek het gehou van uitgaan, danse toe geloop, saam met my vriende uitgaan, gat kuier en so aan. Ek was baie bitterlik lief vir dit gewees. Ek is nie meer lus om iewers heen te gaan nie. Ek het nie eers lus om rond te loop nie, glad nie. Partykeer dan staar ek net in die bloute in, dan wil ek net eenkant sit, alleen sit en dink....."

"I just don't feel like I used to be, I was a very lively person. I liked going out, went to dances, going out with my friends, went visiting and so on. I loved that very bitterly. I don't feel like going anywhere any more. I don't even feel like walking around, not at all. Sometimes I just stare into the blue, then I just want to sit apart, sit alone and think..." (Joeyce);

"Die VIGS takel dit maak my gedaan, dit voel nie ek moet vriende het nie. Ek moet nie met ander mense kommunikeer nie, ek moet net met my twee kinders wees...ek is nie meer soos altyd gaan uit my eie uit....nee ek sit net so by die huis naweke ek sit net by die huis, ek doen my huiswerk ek sit. Ek het nie meer daai gevoel meer soos eers soos ek hom eers gehad het nie. Soos met vrinde of so,

ek voel nie om tussen hulle of as hulle vir my sê hulle gaan vandag na 'n partytjie toe, kom ons gaan. Ek het nie meer sulke belangstellings nie"
"The AIDS batters it exhausts me, it feels like I shouldn't have friends. I shouldn't communicate with other people, I should just be with my two children…I'm no longer like before going out of my own accord…. no, I just sit at home weekends I just sit at home, I do my housework I sit. I no longer have that feeling like before like I had it before. Like with friends or so, I don't feel like being among them or when they tell me they're going to a party today, let's go. I don't have such interests any more" (Hester);

"Toe ek dit gehoor gehoor het, het dit my lewe baie verander. Ek wil nie seker ek wil nie uitgaan nie, ek wil nie buitekant is nie, ek wil nie mense…hulle weet hulle weet ek het nie die siek nie, maar vir my lyk dit almal weet ek het die siek en ek wil nie raakgesien wees nie. Ek het baie in die huis gesit, nooit uitgegaan nie net gesit…. meeste van die tyd is ek maar net by die huis…dan is ek alleen"
"When I heard heard it, it changed my life a lot. I don't want I don't to go out, I don't want to be outside, I don't want people….they know they know I don't have the sick but to me it seems everybody knows I have the sick and I don't want to be noticed. I've sat in the house a lot, never went out, just sat….most of the time I'm just at home…then I'm alone" (Elna).

All three of the above participants are also stating that they are the ones choosing to be by themselves, because of a lack or decrease in interest and desire to take part in former social activities.

In the study done by Hackl et al. (1997), perceived feelings of loneliness were consistently present throughout the interviews conducted with HIV-positive women. These women tend to withdraw from normal social life, social interaction and taking part in social activities. According to Odets (quoted in Dean, 1995), "social networks are being destroyed and lifestyles radically altered for people living with HIV or AIDS, who attempt to cope with a huge accumulation of loss, grief, and its attendant depression, isolation, discouragement, and guilt" (p. 290).

Maggie, a respondent in the current study, states her withdrawal from people close to her as follows:
"…nadat ek gehoor het ek is HIV+ het ek baie stil geraak soos ek nog nooit was nie. Ek dink ook baie en ek ek konsentreer nie lekker op dinge soos voorheen of dinge wat mense vir my sê of wat

miskien voor my gebeur of so nie, want dit vat 'n bietjie my aandag weg. En ek is nie meer dieselfde nie...ek loop nie meer so in die rondte soos eers nie, ek kan nie meer party aande slaap nie, ek is rusteloos. As ek nog iemand kry om saam mee te gesels, soos my vriend, sal ek nog gesels, maar ek um in ander woorde ek...hy gesels, maar ek luister nie eers wat hy sê nie. Al waarop my aandag is, is op wat die suster vir my gesê het HIV positief, HIV positief. Ek meen amper soos 'n masjien in my kop. Dan moet hy aan my stamp, dan skrik ek dan is ek wakker. Dis amper of ek aan die slaap is as iemand met my praat of so..."

"... after I'd heard that I'm HIV+ I became very quiet like I never used to be. I also think a lot and I I don't concentrate so well on things like before or things that people say to me or that perhaps happen in front of me or so, because it takes away my attention a bit. And I'm no longer the same ... I don't go around like before, I can no longer sleep some evenings, I'm restless. If I still get someone to talk with, like my friend, I will still talk, but I um in other words I... he talks, but I don't even listen to what he says. My attention is only on what the sister said to me HIV positive, HIV positive. I mean almost like a machine in my head. Then he has to nudge me, then I get a fright then I'm awake. It's almost as if I'm asleep when sombody talks to me or so...".

The above statement also reveals that Maggie is isolated even in the company of other people communicating with her. She cuts herself off from others by not paying attention, by processes that seems almost dissociative.

It appears that social interaction with family members and friends yields some emotional relief for the participants, but some clearly state that feelings of loneliness always return:

"Ek hou my maar besig en so. Dit is eintlik wanneer ek alleen is, wanneer mens so sit en dink aan 'n ding. Wanneer ek nie kan slaap in die nag nie, dan dink mens mos aan sulke dinge...Want kyk hulle gesels, loop dans en ek, dan sit ek maar net daar. Ek voel so terug het nie geselskap en so nie"

"I just keep myself occupied and so. It's really when I'm alone, when one sits like that and thinks of a thing. When I can't sleep at night, then one thinks of such things ... Because see they are chatting, go dancing and me, then I just sit there. I feel so withdrawn don't have company and so" (Ann);

"Hulle (her friends) is altyd by my, hulle gesels oor ander dinge. As ek weer allenig is dan dink ek daaraan...toe gaan ek na my kamer toe, toe gaan huil ek my aan die slaap..."

"They (her friends) are always with me, they chat about other things. When I'm on my own again, then I think of it...then I went to my room, then I cried myself to sleep..." (Mariana);

"....partykeer is dit maar moeilik wanneer jy stil sit. Dan is dit nou wanneer jy tussen mense is moet ek my weer iemand anders wees, wat kan lag en praat en um kan 'n grap maak. En ek dink dit is seker ook dit wat my meer regop hou ek...al het ek die wete in my, maar ek probeer om te lewe saam met die mense. Dat ek nie heeltemal daar is um daar is sommige wat ek kan tussen mense wees en dan is ek net heeltemal um voel ek net heeltemal weer ver van hulle af"
"...sometimes it's hard when you sit still. Then it is when you're among people I must again be someone else, who can laugh and talk and um can make a joke. And I think it's probably also that which keeps me more upright ...even if I have the knowledge in me, but I try to live together with the people. That I'm not totally there um there are some that I can be among people and then I'm just totally um I feel just totally far away from them" (Sylvie).

The above response of Sylvie supports Stuewe-Portnoff's (1988) belief that interaction with people in ways that are inharmonious with the lonely person's inner life, amounts to exchanging alienation from others for alienation from the self. Thus interacting without sharing inner emotions and experiences may lead to a shallow or superficial existence. In the study conducted by Jue (1994), many of the long-term AIDS survivors express feelings of loneliness, in spite of the fact that some of them receive support and care from close friends and family.

4.1.1 Social isolation

According to Weiss's (1973) postulation of two forms of loneliness, emotional isolation and social isolation, all the participants in the present study experience social isolation, as already illustrated by the quoted statements. Social isolation is not only caused by the lack of meaningful social interaction, social inadequacy and alienation, but also by the absence of a supportive social network (Rokach, 1997; Weiss, 1973). Research conducted by Jones and Moore (quoted in Rokach, 1997), shows a substantial inverse relationship between the availability of social support and loneliness. In the present study, Nossie describes how she has to cope with her baby with full-blown AIDS without any support from friends or relatives. She says:

"Nee niemand nie ek is maar al een. As sy siek raak moet ek maar self 'n ryding gaan soek om vir ons hospitaal toe te bring en so. Daar is niemand eintlik wat my wat vir my 'n kansie gee, ek vat vir

haar en rus jy bietjie ook. Ek doen daai so daar is niemand daar is niemand rêrig waar...Ek is haar ma ek moet dit doen, want as ek dit nie doen nie dan wie anders gaan dit dan doen. Want daar is nie een wat my kan aflos by haar nie"

"No nobody I'm the only one. If she gets sick I have to go and look for transport myself to bring us to the hospital and such. There's nobody really who gives who gives me a breather, I take her and you also rest a little bit. I do this so there's nobody there is really nobody...I'm her mother I have to do it because if I don't do it then who else is then going to do it. Because there's nobody who can relieve me with her".

As previously mentioned, women with HIV are socially isolated from the health care system by factors such as unemployment, being single mothers, lack of convenient transportation and substance abuse. In the present study most of the women experience a lack of social support as a result of these factors, although their need for support in coping with daily responsibilities is clearly stated:

"Die siekte maak my so moeg ek kan net 'n een kan water kom haal het, dan voel dit ek moet nie meer wasgoed was nie. Kan ek nie iemand vra om my te kom help nie?"

"The illness makes me so tired if I've just fetched one jug of water, then it feels I shouldn't carry on doing the washing. Can't I ask someone to come and help me?" (Hester);

"Dan voel ek baie sleg oor, nou lê ek daar, wie gaan vir my omgee? Wie gaan vir my kom help miskien met die kind...of miskien die huis skoon maak of so...?"

"Then I feel very bad about it, now I'm lying there, who's going to care about me? Who will come and help me perhaps with the child ...or perhaps clean the house or so...? (Rosy).

Of all the participants in the current study, only Maggie and Hester feel that their partners, who are also HIV+, provide them with adequate emotional and financial support. Most of the women are unhappy and frustrated with the lack of support and care from their partners. Some of the participants state their feelings as follows:

"Ons praat nie eintlik daaroor nie (their illness), want ek kan nie met hom praat nie...dit is baie moeilik. Hy is baie moeilik, hoe kan ek sê hy is van humeur...so is hy. Nee wat, my man is maar...hy staan my nie eintlik by nie. Gister wanneer het ek gesê ek is...ek het gesê ek is kleuterskool onderwyser, ek is ek is onderwyser, ek is klasjuffrou, ek is ma, ek is pa, ek is alles...ek moet alles doen...Ek sal graag wil hê dinge moet 'n bietjie verander in die huis. My man sy drinkery los, dis hoe

ek voel. Hy moet 'n slag sy manlike pligte nakom, dan kan ons twee mekaar bystaan. Ek meen hy het ons baie uitgeneem annerdag, dit gebeur nie meer nie. En daars geld en geld vir drank. Ek het, ek was al van plan om hom te los, rêrig waar…"
"We don't really talk about it (their illness), because I can't talk to him …it's very difficult. He's very diffcult, how can I say, he has a temper…that's how he is. No, my husband is just ….he doesn't really assist me. Yesterday whenever I said I'm … I said I'm nursery school teacher, I'm I'm teacher, I'm class teacher, I'm mom, I'm dad, I'm everything …I have to do everything… I'd like things to change a bit in the house. My husband to stop his drinking, that's how I feel. Hy must for once fulfil his male duties, then the two of us can assist each other. I mean he took us out a lot in the past, it doen't happen any more. And there's money and money for dinrk. I have I've at times intended leaving him, really …." (Ann);

"Ek sal eider sorg vir ons vir iets om te eet as wat ek drank moet koop, maar hy verstaan nie sulke dinge nie...Dan moet ek saam met die huisvrou in die huis praat dan praat ons saam met hom. Hy werk nie vir my nie, hy slat my…"
"I'd rather see to it that we have something to eat than I would buy drink, but he doesn't understand such things … Then I have to talk to the housewife in the house then we speak to him together. He doesn't work for me, he hits me…" (Mariana);

"Hy het somtyds vir my wat hy vir gewerk het, voor ons uitgevind het van HIV, het hy vir my sy hele salaris gegee, maar nou wat hy nou 'n toelae kry, gee hy miskien R150 miskien…wat hy eers vir my gedoen het, gebeur nie nou meer nie"
"He sometimes used to give me that he worked for, before we found out about HIV, he gave me his whole salary, but now that he's getting a grant, he gives perhaps R 150 perhaps … what he used to do for me, doesn't happen any more" (Rosy);

"Met my man kan ek tog nie regtig praat nie, hy sal net ek weet ek meen omdat ek ook nie weet hoe hy regtig voel nie"
"I can't really talk to my husband, he will just I know I mean because I also don't know how he really feels" (Sylvie);

"Dit is 'n aan en af verhouding, dit is nie eintlik 'n verhouding nie, want hy ondersteun nie vir my nie, hy help nie vir my met daai klein dingetjies nie. Soos wat my kind nou op die oomblik in die hospitaal lê, was hy net een keer daar by haar…Die min belangstelling wat hy het aan sy kind. Hy hy ondersteun my baie min eerlik waar hy ondersteun my baie min. Weet jy somtyds voel ek so ek kan iets doen aan hom. Verstaan, hy maak my so innig kwaad, want ek moet so alleen staan terwyl dit ons altwee se probleem is…Hy moet net 'n bietjie liefde en bietjie bystand vir my gee en dis al…"

It's an on-and-off relationship, it's not really a relationship, because he doesn't support me; he doesn't help me with those little things. Like my child lying in the hospital at the moment, he's only been to her once....The little interest he has in his child. He he supports me very little truly he supports me very little. You know sometimes I feel I can do something to him. Understand, he makes me so deeply angry, because I must stand so alone while it's our problem for the two of us... He must just give me a bit of love and a bit of support and that's all..." (Nossie).

According to Kneisl (quoted in Gillman & Newman, 1996), HIV-infected women must deal with sources of stress and anxiety different from those of infected men, for the reason that they more often than not have fewer economic resources, more role responsibilities (e.g. family, children, household), and less social and community support structures than men. Kaspar (quoted in Gillman & Newman, 1996) emphasises that women, who are generally socialised to be nurturing, do not always receive the same level of emotional support from their partners as do heterosexual married men with AIDS. Therefore women have been directly infected and affected by HIV and AIDS as sufferers or partners and carers of people with HIV and AIDS.

All of the partners of the above participants are also HIV-positive. While rereading the stories of the participants, the researcher has hypothesised that many of the partners of these women are most probably using denial as a coping strategy. According to Hackl et al. (1997), denial is an emotion-focused strategy characterised by the use of distractions, blocking or blunting techniques and non-acceptance of the HIV diagnosis and its consequences. Studies conducted by Kalichman et al. and Kelly et al. (quoted in Pequegnat & Stover, 1999) show that HIV-infected men who have less effective coping strategies are more likely to continue to engage in higher-risk behaviours. In the present study the participants mainly complain of their partners abusing alcohol and becoming verbally and / or physically abusive. Some of the participants describe their need and efforts to discuss their concerns about their HIV status and related problems with their partners. Their partners' denial of being HIV+ and unwillingness to respond to these requests also contribute to their dissatisfaction with their relationships and may lead to feelings of loneliness and isolation.

Results of the study on loneliness conducted by Rokach & Brock (1997) support the widely held belief that men have difficulty getting in touch with their feelings and admitting vulnerability, and thus they deny their loneliness because they perceive being lonely as a social and personal failure. According to Rokach and Brock (1997) and Rokach (1996), women experience loneliness differently, mainly in the intensity of pain they perceive and report, as well as their lesser tendency to use denial and self-deprecation.

4.1.2 Emotional isolation

According to Weiss (1973) and Rokach (1997), people experiencing the loneliness of emotional isolation are apt to experience a sense of utter aloneness and emotional distress as well as feelings of abandonment and rejection, whether or not the companionship of others is in fact accessible to them. In the present study feelings of emotional isolation are described by some of the women:

"Ek worry ook eintlik nie met hulle (family members) nie, ek sit maar eenkeer alleen daai kant. Dan kyk ek maar TV, ek worry mos nie....Maar ek het nie eintlik chommies hier nie...Nee ek is maar so alleen...alleen alleen stoksiel alleen....As ek so alleen stil sit, dan praat ek so alleen uit my eie uit so alleen. Dan dink ek ai hoekom moet dit dan met my gebeur so aan. Here help en so aan met my swak liggaam. Daar's niemand nie, net ek alleen met God alleen, stap ek die pad...Daar's niemand niemand nie"

"I don't really involve myself with them (family members), I just sit alone that side. Then I just watch TV, I'm not worrying ... But I don't really have pals here...No I'm just so alone ... alone alone all alone...When I sit so quietly alone then I talk so alone out of myself so alone. Then I think why should this be happening to me so on. God help and so on with my weak body. There's nobody, just me alone with God alone, I'm walking the road. There's nobody nobody" (Bertha);

"Om die waarheid te sê ek weet nie ek kan nie eers dink nie of ek nog kan praat oor 'n lewe wat ek nog nie of watse lewe het ek? Ek is net iemand wat aangaan van dag tot dag en en... um en verder lewe ek nie... ek is nie, ek is die heeltyd maar net ongelukkig. Ek voel die heeltyd maar net um... ek is alleen en ek um ... kan nie met mense of ek is baie keer is ek um... so of ek nou ou is ek vrede en

um môre oormôre dan het ek 'n buie oor my wat ek wat ek self nie verstaan nie. Dat ek maklik met mense nie kan ek wil net nie met hulle te doenig wees nie"
"To tell the truth I don't know I can't even think if I can still talk of a life I still have or what kind of life do I have? I'm just somebody who goes on from day to day and and ...um and beyond that I don't live... I'm not, I'm just unhappy the whole time. I feel the whole time just um...I'm alone and I um...cannot with people... or I'm many times I'm um ... so as if now I'm peace and um tomorrow or the day after then I have a mood over me that I don't understand myself. That I can't be easily with people I just don't want to be involved with them" (Sylvie).

Sylvie also states that she has a need for an intimate relationship with a person with whom she can share her real feelings. She says:
"Ja baie kere mis ek soos 'n verhouding, maar ek...breek maar myself seker self af en um ek het al um 'n mansvriend gehad teenoor wie ek baie ernstig gevoel het. En dat ek gevoel het maar as ons moet um 'n regtige verhouding aanknoop dan kan dit skadelik wees en ek weet nie wat dit gaan, dit gaan net nie werk nie...Ek baie kere dan uh dan voel ek ek is nou is ek heeltemal leeg, ek...het die gevoel of um dit is altyd op my of so...Ek het nie regtig vriendinne daar nie, so met wie ek nou sal lekker intiem gesels of so"
"Yes many times I miss like a relationship, but I ... suppose I break myself down and um I have had um a male friend that I felt very seriously about. And that I felt if we had to um start a real relationship it could be harmful and I don't know what it will, it's just not going to work...Many times then I um then I feel I I'm now totally empty, I ... have the feeling that um it's always on me or something like that ... I don't really have girlfirends there, with whom I can chat intimately or so".

According to Folkman, Chesney, Pollack and Phillips (quoted in Pequegnat & Stover, 1999) many patients do not have the emotional energy to invest in a romantic relationship, because of ongoing health problems, fears of rejection or of infecting others, and loss of emotional stamina. This may lead to social isolation and loneliness and to problems with the self-concept of women, such as attractiveness and sexuality.

The above statements show the psychological distress and emotional turmoil and isolation that HIV/AIDS can cause women. According to Macks (1987), many HIV-infected persons describe their distressing feelings as a roller coaster of emotions or

mood fluctuations, compounded by an overpowering sense of hopelessness and helplessness.

4.2 Psychological consequences of loneliness - depression

Research results on loneliness have generally shown a positive connection between the subjective experience of loneliness and impaired mental health, including neuroticism, low self-esteem, depression, anxiety, psychosomatic concerns, interpersonal hostility / aggression and paranoia (Jackson & Cochran, 1990; Rokach & Brock, 1998; Rokach, 1996).

Relationships between depression and loneliness have particularly been emphasised in the literature (Peplau & Perlman, 1982; Jackson et al., 1990). According to Peplau and Perlman (1982) the prototype of a lonely person is itself nested within the prototype of a depressed person. This relationship suggests that it is more probable for a lonely person to complain of feeling depressed than it is for a depressed person to complain of feeling lonely.

All the participants in the present study describe intense feelings of hopelessness and helplessness, because of the incurability of their illness, the uncertainty about how long they will live, and the eventual consequences of dying. Some of the participants state their feelings as follow:

"Ek voel amper soos 'n verstoteling. Nou dink ek daaraan ek is sieklik en ek makeer iets wat niemand meer vir my kan genees nie en nie eers God nie. Daar is nie medikasie wat vir my voorgeskryf is nie...As ek so daaraan dink nê dan, dan wil ek sommer lê...want dit is hartseer. Maar ek ek kan maar huil, maar ek kan nie die pyn, die hartseer en die siekte kan ek nie weg huil nie. Want dit is iets wat vir altyd by my gaan wees. Dit is, dit is baie diep in my in..."

"I almost feel like an outcast. Now I'm thinking of it that I'm sickly and there's something wrong with me that nobody can cure for me any more and not even God. There's no medication that has been prescribed for me... If I think of this, then I just want to lie down...because it's sad. But I I can cry, but I can't cry away the pain, the sadness and the illness. Because that's something that's going to be with me always. It is, it's very deep inside of me...." (Maggie);

"En ek het vir myself gesê, Here Here help my en verlos my van die siekte, maar omdat ek weet daar is nie 'n verlossing nie en daar is niemand wat my kan genees nie...maar dit voel net vir my dinge gaan nie verander nie. Moet ek kan nog elke dag elke, ek raak moedeloos...ek bly aan't siek ek raak nie gesond nie. Wat moet ek dan nou nog doen, ek probeer my bes, ek gebruik my pille, ek gebruik salf en goeters wat ek kry by die kliniek, maar maar niks help dan nie...Ek weet net nie maar hierdie HIV siekte, dit voel vir my as ek sommige tye dink dan voel ek jinne ek gaan gesond raak, maar dan net die next dag weer dan voel ek weer so af en so teneergedruk, net soos een wat net wil huil..."
"Ánd I've said to myself, God God help me and deliver me from the illness, but because I know there's not a deliverance and there's nobody who can cure me ...but it just feels to me that things aren't going to change. Must I still every day every, I get despondent... I keep on being ill I don't get well. What more do I have to do, I try my best, I use my pills, I use oitnment and things I get from the clinic, but but nothing helps... I just don't know but this HIV illness, it feels to me that sometimes I think gosh I'm going to get well, but then the very next day then I again feel so off and so depressed, like one who just wants to cry ..." (Hester);

"En hoe lank soos...ag ek lewe tog maar van dag tot dag, hoe lank gaan ek nog lewe...want ek bly dink tog maar hoe lank gaan ek nog lewe, ek is vandag gesond môre oormôre kan ek net weg wees. En maar ek dink altyd daaraan en nou nog meer um, hoe lank het ek nog om te lewe, hoe lank kan ek nog so aangaan. Dis soos hoe ek partykeer voel, maar ek moet net tou opgee net alles laat los, want alles is so verniet..."
"And how long like....oh, I'm just living from day to day, how long am I still going to live ...because I keep thinking but how long I'm still going to live, I'm healthy today but tomorrow or the next day I can just be gone. And I'm always thinking of that and now even more um, how long do I still have to live, how long can I still carry on like this. That's how I feel sometimes, but I must just give up just let go of everything, because eveyrhing is so in vain..." (Sylvie).

As has been indicated in the literature (Friedman et al. quoted in De Gouveia, 1984; Young quoted in Peplau & Perlman, 1982) and supported by the partcipants' statements in the present study, loneliness and isolation or repeated rejection can lead to feelings of hopelessness and helplessness, self-blame and finally to depression. Many of the feelings and behaviours described so far by the participants can be evaluated as symptoms of depression, inter alia feelings of helplessness and futility, hopelessness about the future and persistent sadness, impaired capacity to perform their daily work and other activities, withdrawal from

friends and family and a loss of interest in social interaction and activities. Most of the participants previously described how their psychological status and daily functioning changed for the worse after their HIV/AIDS diagnosis. For the partcipants in the present study, experiences of loneliness have most probably contributed to their depressed feelings and decline in daily functioning.

Kaplan et al. (1997) found in their study that depression scores were higher among women diagnosed HIV-positive for two years or less, among those with AIDS, among those with less income and education, and among those who were never married. In the current study all of the participants have low income and education levels, eight of the eleven participants were diagnosed HIV-positive for two years or less and only three are married, of whom one has been separated from her husband for more than a year. This further indicates that the majority of the participants are most likely experiencing serious depressive symptoms that are primarily the result of being emotionally and socially isolated.

4.3 Causes of loneliness

As discussed in the literature review, Rokach and Brock (quoted in Rokach, 1997) propose a general model, consisting of five factors, for the perceived causes of loneliness. The last three factors of this model reflect the causes of loneliness most often stated by the participants in the present study, namely unfulfilling intimate relationships, changes and loss of important relationships due to iself isolation, and social marginality that can lead to being isolated and rejected by others. Because of these factors, the majority of the participants in the present study do not experience common group cohesiveness or share emotions and thoughts regarding the diagnosis with important others. According to Rokach and Brock (1998) this interpersonal alienation can precipitate loneliness that can lead to the development of physical, psychological and behavioural problems and conditions such as depression.

4.3.1 Guilt and fear of infecting others

According to Chinkanda (1990), guilt and fear of infecting others are very important emotions that a person with HIV/AIDS has to deal with and may contribute to social withdrawal from close family and friends. In a study conducted by Sewpaul and Mahlalela (1998), the participants describe how they felt isolated, alone and overwhelmed with guilt at having passed on a death sentence to their children. The intense guilt was the most difficult emotion for these women to negotiate. According to Chachkes (1987) and Gillman and Newman (1996) women express tremendous guilt over unintentionally transmitting the disease to their child, anticipating the abandonment of their non-infected children or stigmatising their children because of their disease. Mothers with HIV infection participating in the study conducted by Faithfull (1997) also mention fears of infecting children through casual contact.

In the current study it is quite surprising that none of the participants reveal guilt feelings for infecting their children, although they are very concerned about their children's present and future wellbeing. The participants who have children with symptomatic HIV or AIDS describe intense emotional pain and feelings of helplessness because of their children's suffering. Four participants (Maggie, Mariana, Joeyce and Rosy), however, disclosed guilt feelings for infecting their partners with HIV. Some of the participants reveal fears of infecting people with whom they come into contact in their daily lives. Nossie says:

"Sê ek wil by mense gaan gaan kuier nê en um ek is besig om kos te maak, nou sny ek my hand raak en en ek het nie vir hulle gesê ek is HIV+ nie, verstaan...en hulle eet miskien die slaai wat ek gemaak het en ek sê niks vir hulle nie. My vinger bloei en hulle help vir my, maar daai bloed miskien nou daar en iemand het dalk 'n stukkende plekkie. Nou kry hulle dit of so..."

"Say I want to go go and visit people and um I'm making food, now I cut my hand and and I haven't told them I'm HIV+, you understand ... and perhaps they eat the salad I've made and I don't say anything to them. My finger bleeds and they help me, but that blood there perhaps and somebody may have an open cut. Now they get it or so ...".

One participant fears that she or her HIV+ child will infect others. Hester says:

"Ek wil nie ander mense aansteek ook met die siekte nie. Ek wil met my kinders...hulle moet nie kontak maak met bloed goed, bloed klere of iets of as iemand vir haar seergemaak het en haar vingertjie bloei of hulle het gekap teen mekaar se koppe. Die een se neus bloei en die ander een se neus bloei, dan voel dit net vir my ek is so bang...Ek is bang my kind kan die ander kinders aansteek deur die bloed aanmekaar te raak. Dan vat ek vir haar weg en ek maak vir haar skoon...dat sy nou net eenkant weg van mekaar af is"

"I don't want to infect other people with the illness as well. I want to with my kids...they musn't make contact with blood things, blood clothes or something or if someone has hurt her and her finger bleeds or they bumped their heads against each other. The one's nose is bleeding and the other one's nose is bleeding, then it feels to me that I'm so scared... I'm scared my child could infect the other children through the blood touching. Then I take her away and I clean her up ...that she is just apart away from the others".

Hester also fears infecting her healthy child. She says: *"Want ons is bang ons kan ons seuntjie wat dit nou nie het nie...as ek 'n seerplek op my het ...ek is skoon so bang. Ek maak dit toe, want ek wil nie vir hom vir hom besmet met die virus nie. En even as hy 'n seer het, ek bring vir hom kliniek toe dat die susters net kan kyk daarna, want ek voel so bang ek wil nie ander met dieselfde pynigheid wat ek deurgegaan het en nou nog"*

"Because we're scared we can our little boy who doesn't have it ...if I have a wound on me... I'm so very scared. I cover it because I don't want to contaminate him with the virus. And even if he has a sore, I bring him to the clinic so that the sisters can just look at it because I feel so scared I don't want to others with the same pain which I have gone through and still now".

In the study conducted by Faithfull (1997) almost all the participants fear infecting others through everyday activities and this contribute to social withdrawal, which enhance feelings of loneliness.

4.3.2 Stigmatisation

In the literature it is emphasised that HIV/AIDS carry a powerful negative stigma that distinguishes it from other chronic diseases. All the participants in the present study are aware of the stigmatisation attached to HIV and AIDS and the negative

consequences thereof. Because of AIDS being a life-threatening disease with no known cure, people fear becoming infected with the HIV virus. Ann says:

"Want dit is vir die mense, dit is 'n verskriklike siekte vir ander...Ek meen mens sien mos dinge op die TV en op die nuus...daai oor die siekte en mense gesterwe van die siekte en daar is nie geneesmiddels en daai goed nie"

"Because to the people it's, it's a terrible illness to others... I mean one sees things on the TV and on the news ... that about the illness and people died of the illness and there are no cures and such things".

Sonja and Bertha are the only two participants who mentioned the stigmatisation attached to HIV/AIDS because of the virus being sexually transmitted and the perception that the disease is caused by immoral behaviour. They respectively say:

"Ek het baie seer gevoel...hulle sal dit so vat um dis jou eie skuld, want jy het rond gegaan en... toe kry jy nou daai siekte..."

"I felt very hurt... they will take it as um it's your own fault, because you slept around and ...then you got that illness..." (Sonja);

"Ek het vir niemand vertel nie, vir niemand nie, want ek voel net skaam met my gesig...net skaamte. Maar dit is nie lekker nie, want ek het dit nie geweet nie, regtig nie, ek het dit nooit geweet nie... Ek wil vir niemand vertel nie, want dit is 'n skande..."

"I told nobody, nobody, beause I just feel ashamed with my face ... just shame. But it's not nice, because I didn't know it, really, I never knew it... I don't want to tell anybody, because it's a disgrace...." (Bertha).

According to Sherr (1995), the blaming of people with HIV- and AIDS-related illnesses for their condition has been widely reported. In the study conducted by Mc Ginn (1996), all the participants express frustration about irrational fears of contagion and negative attitudes regarding perceived immoral behaviour they encounter from members of their community.

According to Walker et al. (1996, p. 50), stigma attaches to the social or cultural groups into which many people with HIV/AIDS fall, the physical disfigurement associated with AIDS, the cognitive decline of people with AIDS, the lack of a known

cure, the often unrealistic fear of contagion, and some people's perception of immorality associated with the disease. Zlotnik states that, "...persons affected by AIDS are multiply stigmatised because AIDS often is perceived by society as shameful, mysterious, contagious and sexually transmitted" (1987, p. 2). In view of the fact that the stigma is so severe, it alienates women with HIV or AIDS from their families and community supports when they are particularly vulnerable and this leads to extreme experiences of loneliness (Chachkes, 1987; Macks, 1987). In the literature it is also stated that a woman with HIV or AIDS could experience severe emotional distress, because of the stigmatisation attached to both the disease and her state of loneliness (Rokach & Brock, 1998).

4.3.3 Fear and shame of disclosure

All the participants in the present study reported fear of disclosing their HIV-status to family members and friends because of possible rejection and victimisation. Only one participant, Bertha, clearly states that she does not want to disclose her diagnosis because she feels ashamed of her HIV status:

"Ek wil vir niemand vertel nie, want dit is 'n skande...ek voel net skaam met my gesig...net skaamte"
"I don't want to tell anybody, because it's a disgrqce ... I just feel ashamed with my face ...just shame".

Kelly and Lawrence (1988) point out that disclosure of an AIDS-related illness might involve revealing other previously undisclosed information about a stigmatised life-style.

On the contrary, another participant, Maggie, says that she does not experience feelings of shame, but only fears rejection should she disclose her HIV status:

"...hulle gaan bang wees. Hulle gaan sê nee los daai vrou, daai vrou is sieklik. Daarom ek wil nie vir almal dit vertel nie. Ek voel nie skaam daaroor nie, maar ek is bang hulle gaan my naam besmadder"

"... they'll be scared. They are going to say no leave that woman, that woman is sickly. That's why I don't want to tell everybody. I don't feel ashamed about it, but I'm scared they're going to besmirch my name".

All the participants in the current study reveal feelings of intense fear that they would be rejected, insulted or even physically harmed should they disclose their HIV status. The participants describe their feelings as follows:

"Ons wil nie hê die hele wêreld moet weet nie...verstaan u? Nie eers familie nie, anders sal ons vrinde nie meer het nie"
"We don't want the whole world to know...you understand? Not even family, otherwise we'll no longer have any friends" (Ann);

"As ek vir haar sê, ja ma ek het AIDS, dan gaan sy vir my onmiddellik sê maar my kind vat maar jou goedjies en gaan maar. Want ons kan nie saam met jou saam lewe nie"
"If I had to tell her yes mum I have AIDS, she'll immediately say but my child take your things and go... Because we can't live with you" (Maggie);

"....hulle sal nou weer hulle kinders moet met my kinders speel nie. Hulle sal ook nie by my huis wil kom nie, soos gewoonlik met my 'n koppie tee of koffie te drink nie. Hulle sal bang wees om met my te praat...ek voel nie om vir hulle te sê nie"
"... they won't want their children to play with my children. They'll also not want to come to my house, to drink a cup of tea or coffee with me as usual. They'll be scared to talk to me...I don't feel like telling them" (Hester);

"Dan gaan hulle vir my lelik uitskel...of as ek verby hulle stap net so lelik aankyk..."
"Then they're going to call me bad names...or just look at me so nastily if I walk past them..."" (Sonja);

"... ek was te bang om met iemand te praat.....Ek dink in 'n plek soos um die waar ek nou regtig is, sal daar baie beledigende woorde geslinger word na jou toe"
"... I was too scared to talk to somebody... I think in a place like the one I'm in, there'll be many insulting words thrown at you" (Sylvie);

"... Die gemeenskap rondom niemand weet nie, want ek is te bang mense gaan my verstoot as ek nou vir hulle gaan sê. Mense sal altyd na my toe kom en so aan, dan maak ek vir hulle tee. As ek

vir hulle gaan sê dan gaan hulle nie meer by my kom nie. Toe voel ek nou as ek nou vir die mense gaan vertel gaan die mense nooit met my kan kommunikeer of niemand gaan in my belangstel nie"
"...The community around no-one knows, because I'm too scared people will reject me if I had to tell them. People always come to me and so on, then I make them tea. If I had to tell them they won't come to me any longer. Then I felt that if I had to tell the people, the people will never communicate with me or nobody's going to be interested in me." (Nossie);

"....maar hy sal seker nie vir my sê as hy die siek het nie. As hy vir my sê dan sal ek vir hom sê dit is deur my...as ek nou sê dan gaan ons twee uitmekaar uit dan...Miskien slat hy my, maak my seer"
"...but he probably won't tell me if he has the sickness. If he tells me then I'll tell him that it's through me ... if I say that then we two will split up. Perhaps he'll hit me, hurt me" (Mariana);

"Hulle gaan vir my seer maak, hulle gaan vir my dood maak..."
"They'll hurt me, they'll kill me ..." (Joeyce);

"Ek dink hulle sal my verlaat as 'n vriend, want die lewe is maar deesdae so...almal verwerp jou as hulle hoor jy het die siek"
"I think they'll leave me as a friend, because life is like that nowadays ...everybody rejects you if they hear that you have the sickness" (Elna).

Sewpaul and Mahlalela (1998) explored the psychosocial consequences of an HIV-positive diagnosis for 15 mothers, all of whom had babies with symptomatic HIV or AIDS. All the participants experienced intense fear about the disclosure of their HIV status to their families, partners or the public. Some of these women were physically assaulted and beaten up by their partners and family members when they disclosed their diagnosis. Overall (1991) states that a woman who discloses her HIV-positive status to her male partner runs the risk of abandonment, economic impoverishment and possibly even assault. This fear of and experiencing of rejection contribute to loneliness and isolation and consequently to high levels of distress (Chachkes, 1987; Sewpaul & Mahlalela, 1998).

The participants also feel that people will reject them because of their fear of contagion. Maggie, Mariana and Rosy respectively say:

"Kyk vandag is dit mos maar so, mense wil nie saam met jou eet uit een ding uit nie, hulle wil nie saam met jou drink nie, hulle wil nie saam met jou gesels nie, hulle wil nie aan jou vat nie, want jy het AIDS"
"Look today it just is like that, people don't want to eat with you out of the same thing, they don't want to drink with you, they don't want to talk with you, they don't want to touch you, because you have AIDS" (Maggie);

"Hulle sal bang wees om met my te praat…of saam met my te drink of te eet…"
"They'll be scared to talk to me…or to drink or to eat with me…" (Mariana);

"Ek weet nie of hulle bang is vir die mense met HIV of wat nie, maar hulle wil nie naby die mense is met HIV nie…Dan voel ek weer baie sleg en dan dink ek ai, ek het self HIV…"
"I don't know if they're scared of the people with HIV or what, but they don't want to be near the people with HIV…. Then I feel very bad again and then I think oh, I have HIV myself…" (Rosy).

Elna, who disclosed her HIV status to her family members, describes how she experiences the consequences of stigmatization in her daily life:

"Ek mag nie aan die kind raak nie…hulle het vir my straight gesê ek moet wegbly van hulle kind af. Die kind mag niks van my ontvang nie, tensy dit 'n toe ding is…dan sal hulle dit nog vat, maar wat oop is wat ek nou van eet of ek maak nou net 'n piesang oop, dan mag ek nie vir hom afbreek daarvan nie…Maar ek mag nie die kind optel nie en niks nie, maar ek voel seer daaroor maar ek aanvaar dit maar so, ek aanvaar dit maar"
"I'm not allowed to touch the child…they told me straight I must stay away from their child. The child may not receive anything from me, unless it's a closed thing...then they'll still take it, but something that's open that I"m eating from or if I just open a banana, then I may not break off a piece for him…But I'm not allowed to pick up the child and nothing, but I feel hurt about it but I accept it like that, I just accept it".

Elna is also not allowed to prepare food for certain family members, which causes her emotional distress. She says:

"…hy eet nie uit my hande uit nie. Daarom as ek kos koop dan sal sy my eerder vra of sy nie die kos kan maak nie… Nou ek voel baie sleg daaroor, toe sê ek vir mammie, maak mammie maar eider die kos, dan weet ek mos hy gaan saam eet. Al weet hy dit is my kos sal hy saam eet as iemand anders dit maak, maar as ek gemaak het dan eet hy dit nie"
"… he doesn't eat from my hands. That's why when I buy food she'll rather ask me if she can't make the food…. Now I feel very bad about that, then I said to mommy, mommy should rather make the

food, then at least I know he will eat with us. Even if he knows it's my food he'll eat with us if somebody else makes it, but if I made it then he doesn't eat it."

Hester, who still denies her HIV status, although certain family members suspect that she has the disease, describes her experiences of rejection:

"In hulle hele houding kan ek sien hulle wil 'n bietjie 'n bietjie weg van my af wees. Of saam met my in een ding uit was of so maak nie....hulle is weg van my af. Hulle wil nie saam met my uit 'n koppie water drink of so nie. Want van my broer so geskel het oor die VIGS, voel dit vir my baie....dan moet ek maar nie met mense kommunikeer nie"

"In their whole attitude I can see they want to be a bit a bit away from me. Or not wash with me out of the same thing or do something like that...they're away from me. They don't want to drink with me from a cup of water or such. Because since my brother scolded so about the AIDS, it feels to me very ... then I should rather not communicate with people".

As can be seen by the reactions and feelings of the participants in the present study, the decision to disclose an HIV diagnosis places a complex and additional burden on women. Hackl (1997) states that women who share their HIV/AIDS diagnosis with family and friends risk stigmatization (including reactions of fear, shock and blame), isolation (as a result of others' fears of casual transmission and the possibility of desertion), and potential loss of self-esteem (lack of confidence and self-blame). Under these conditions, disclosure can exacerbate the woman's distress rather than mobilize support.

4.3.4 Fear of disclosure and the effect on family members

Most of the participants in the current study also worry and fear that their children may be rejected or insulted by people, including family and friends. Even those participants, who have children with no HIV diagnosis, fear that their children will be treated harshly because of their own HIV status. Ann, who has two HIV-positive children and one healthy child, says:

"Ek is net bang my kinders sal afgeskeep word, hulle gat nie vriende mee het nie, maatjies het nie. En vir die mense se pratery daarvoor is ek bang"

"I'm just afraid that my children will be treated shabbily, they won't have friends any longer, won't have playmates. And the people's gossiping that's what I'm afraid of".

Sylvie, a mother of six children, who is unsure about the HIV status of her two youngest children, states her concern as follows:

"…. maar dit is vir my swaar om te dink dat ek moet 'n siekte ly en ek kan siek word en ek kan dood gaan. En my kinders of mense moet daarvan weet en my kinders miskien daar met die klippe gooi en so.....en hoe gaan hulle daarmee lewe..."

"... but it's hard for me to think I'm suffering from an illness and I can get sick and I can die. And my children or people had to know about it and perhaps throw stones at my children there ... and how are they going to live with that...".

Elna, a mother of an HIV-positive toddler, disclosed her status to her closest family members. She and her child regularly experience rejection from, and are insulted by, certain family members. She says:

"... my kind word weggejaag soos 'n hond, weg van daai deur af. Sy mag nie in daai kamer in nie, sy mag nie naby hulle kind nie...Ek voel baie sleg, want ek ek ek vat dit so hulle kan maar maak met my wat hulle wil, maar sy weet nie wat rondom haar aangaan nie. Sy weet nie sy het die siek nie..."

"... my child is chased away like a dog, away from that door. She's not allowed to go into that room, she may not come near their child...I feel very bad because I I the way I see it they can do to me what they will, but she doesn't know what's going on around her. She doesn't know she has the sickness...".

In the present study it seems that the participants with HIV-positive children experience even higher levels of distress, isolation and loneliness, because of additional fears and concerns that their children might infect others with the disease or that they will be rejected and insulted by others as a result of stigmatisation. According to Dicks (1994), women with HIV/AIDS have fears about how their children and families will be treated, which keep them in a state of denial, hiding and secrecy.

4.3.5 Disclosure and fear of other losses

Studies conducted by Faithfull (1997), Gillman and Newman (1996) and Hackl et al. (1997) report issues of rejection, shame and the potential loss of housing, social supports, children and future relationships as serious emotional concerns for HIV-positive women when they consider disclosure of their HIV status. Most of these issues are also concerns for the participants in the present study.

Some participants mention the issue about the potential loss of housing if they should disclose their HIV status. Nossie reveals her concern as follows:

"Maar as hulle dit uitvinne dan gaan dan gaan dit vir my dryf na baie dinge toe...soos byvoorbeeld ek sal maar nou iewers moet gaan wegtrek na 'n ander plek toe. Daar waar mense natuurlik nie weet nie. Maar dit gaan my nog seer maak"

"But if they find out about it then it then it will drive me to many things... for example, I would rather have to move away to another place. There where people don't know of course. But it will still hurt me".

Joeyce, whose HIV status is known by her close community, has actually been asked to leave her home. She says:

"En dieselfde aand toe het hy (the owner of the farm) al die plaasmense bymekaar kom en toe het hy dit vir hulle vertel. En nou een middag toe stop hy net by my. Stop hy toe sê hy...sorg net dat jy jou klere nou pak ek staan hierso en maak dat jy wegkom asseblief"

"And the same evening he (the owner of the farm) called all the farm people together and then he told them about it. And one afternoon he just stops next to me. He stops then he says...just make sure that you pack your clothes now I'm standing here and be off, please".

According to Faithfull (1997), the participants in her study fear that they could lose their housing and this made secrecy about their diagnosis imperative.

In the current study one of the participants fears being separated from her child if she should disclose her HIV status. Maggie says:

"...want as ek nou vir hom gaan sê dat ek AIDS het, dan gaan die kind vir my bang raak. My ma gaan ook vir hom aanmoedig om nie na my toe te kom nie. So as ek nou vir hom sê sal my ma hom

baie vêr van my af hou. Want sy vat dit so net een mistake dan kan hy miskien betas word...en dan verloor sy 'n kleinkind"
"...because if I had to tell him that I've got AIDS, the child will become scared of me. My mother will also encourage him not to come to me. So if I tell him my mother will keep him very far from me. Because the way she sees it, just one mistake then he can perhaps be touched ... and then she loses a grandchild".

Faithfull (1997) reports that the women in her study, whom decided not to disclose their HIV status to family members, fear losing the custody of their younger children or even being abandoned by their older children.

4.3.6 Disclosing to their mothers

Research indicates that disclosure to close family members, like a mother figure, can bring about emotional relief and lessen esperiences of loneliness and associated psychological symptoms such as depression (Sewpaul and Mahlalela, 1998).

Seven of the eleven participants' mothers are still alive. Five of these women decided not to disclose their HIV status to their mothers because of fear of rejection and criticism. Maggie, Hester en Bertha respectively say:
"Sy (her mother) wil graag hê ek moet vir haar self sê, maar ek is 'n bietjie bang....net nou maar verwyt sy my en gooi my weg en dan dink ek wat gaan van my kind word"
"She (her mother) wants me to tell her myself, but I'm a bit scared... what if she blames me and throws me away and then I think what will become of my child" Maggie);

"Jy kan niemand in jou vertroue neem nie, niemand nie. Dit is waarom ek besluit het ek voel nie eers om vir my eie ma te sê nie, dat dit is so nie.....En dalk voel ek ek ek het so siek geword lat dit lyk ek moet vir haar sê, maar ek het net my gebed gedoen en gedink sy kan dit maar hoor as ek weg is.....as ek dood is, maar ek voel dit nie om vir haar nou te sê nie"
"You can take nobody into you confidence, nobody. That why I decided I don't even feel like telling my own mother that it is like this...And perhaps I feel I I've become so ill that it seems I have to tell her, but I just said my prayer and thought she can hear it after I'm gone...when I'm dead, but I don't fee like telling her now" (Hester);

"En toe het ek mos nie vir my ma vertel nie, oormôre dan sê die mense ek het ek het daai....dit gat mos gif wees...."
"And I haven't told my mother, the day after next then the people will say I have I have that ... that will be poison..." (Bertha).

Two of the participants, Joeyce and Elna, who have full-blown AIDS, told their mothers of their HIV status just after they had been diagnosed. Both women complain that their mothers at times scold and criticise them for being HIV-positive, but most of the time they are supportive and caring. Elna was at first unhappy with her mother's reaction. She says:

"Ek het hulle (her parents) ondersteuning nodig...en hulle het dit aanvaar, maar die probleem was net gewees toe ek my ma vertel, het my ma weer vir ander mense vertel by die werk...bure vertel. En ek het nie gelukkig daaroor gevoel nie, want ek vat dit so dit is 'n private besigheid, dit is 'n huis situasie, hoekom moet ander weet"
"I need their (her parents') support...and they've accepted it, but the problem was just when I told my mother she then told other people at work...told neighbours. And I didn't feel happy about that, because the way I see it it's a private matter, it's a home situation, why should others know".

Joeyce states that her mother was initially shocked, but accepted her illness afterwards and even tries to protect her from stigmatization:

"My ma-hulle was eers geskok gewees.... My ma het vir hulle gesê maar dit, sy kan drink saam met julle, sy kan eet uit een bord en vurke van julle. Dit is nie aansteeklik nie. Jy gaan mos nie seksueel om met haar dat jy dit gaan kry nie, het my ma vir haar verduidelik"
"My mother and them were shocked at first...My mother told them but she can drink with you, she can eat from one plate and forks of yours. It's not contagious. You don't have sex with her so that you will get it, my mother explained to her".

In the study conducted by Sewpaul and Mahlalela (1998), six of the 15 women disclosed their status to their mothers who, despite the women's fears, were supportive of them. One woman in this study described her entry into a support group, and her subsequent disclosure to all her family members, as the turning point in her life.

4.3.7 Secrecy as coping mechanism

All the participants in the present study describe their HIV status as a personal and private matter. Some participants call it their secret. Most of the participants hide their diagnosis from very close family members and friends because of fear of being stigmatised. Some of the participants describe their feelings as follows:

"Ek wil nie eintlik hê hulle moet uitvinne wat makeer ek nie. Dit is 'n geheim tussen my en my kêrel en God. Verstaan jy...Ek wil nie vir almal dit vertel nie...ek is bang hulle gaan my naam besmadder"
"I don't really want them to find out what's the matter with me. It's a secret between me and my boyfirend and God. Do you understand... I don't want to tell this to everybody...I'm scared they're going to besmirch my name" (Maggie);

"Een chommie sal vir die ander ene vertel...sê die ander ene het jy gehoor van dit. Nee mens kan nie met sulke dinge mense in jou geheim deel nie"
"One friend will tell the other...say to the other have you heard about this. No, one can't with such things share your secret with people" (Joeyce);

"Dan gaan ek dit elke dag hoor en hulle sal ook nie meer met my dieselfde wees nie...maar dan dink ek by myself, dis soos iets wat my weerhou. Ek moet dit nie doen nie, want dit is die grootste fout wat ek in my lewe gaan doen"
"Then I'll hear it every day and they'll also not be the same with me any more...but then I think to myself, it's like something keeping me back. I musn't do it, because it'll be the biggest mistake I'll make in my life"(Hester);

"...my familie ek vertrou hulle nie om met hulle te praat nie, want hulle lap te veel.....ek het nou al gevoel daar was al um woorde wat geslinger is na my toe"
"... my family I don't trust talking to them, because they blab too much...I have felt that there have been um words thrown at me" (Sylvie).

Several of the participants in a study conducted by Sandstrom (1993) came to view physical and social isolation as the best means available to them for escaping from both these interpersonal difficulties and their own feelings of ambivalence. By withdrawing from virtually all interaction, they sought to be spared the social

struggles and psychic tension that could be elicited by others' recognition of their condition.

It seems that for one participant the only way to cope with her situation is to pretend that everything is fine and not to share her secret with others. Nossie says:

"…. dat dit wat ek beleef, dat ander kan sien maar nie weet nie. Hulle sien vir my, maar hulle weet niks van my nie…Almal vra vir my wat makeer my kind dan werklik, hoekom is my kind so baie siek. Ek kan nie vir hulle gaan sê nie…."

"… that what I'm experiencing, that others can see but not know. They see me, but they know nothing about me…Everybody asks me what is really wrong with my child, why is my child ill so often. I can't go and tell them…".

According to Faithfull (1997), the stigma of HIV/AIDS leads some women to hide their diagnosis, even from close family members. Some of the participants in a study conducted by Hackl et al. (1997) used isolation to avoid rejection by others and to protect themselves. These women suffer in isolation on account of the stigma placed on the disease by society and their own communities. While this silence and withdrawal lead to isolation and lack of support, it may also have a protective function, bolstering denial and preventing women from becoming fully aware of the painful consequences of being infected (Faithfull, 1997). Although the participants in the present study revealed many coping strategies, secrecy and social withdrawal, because of stigmatization, are the strategies most often used.

Concurrently with the participants' fear of disclosure, secrecy and social withdrawal, many of them reveal a strong need for acceptance and psychosocial support. Elna says:

"Dit pla vir my ja, ek wil nie met so aandag aangekyk word nie, omdat ek aanvaar ek het dit, maar ek dink nie daaraan nie…verlang ek ander moet ook vir my behandel soos enige ander mens behandel word. Ek wil nie hê hulle moet vir my kyk met daai aandag of my jammer kry nie. Um ja ek wil graag hê hulle moet lief wees vir my, dam liefde is die ding wat ek die meeste mis in my lewe in en dan dis wat ek wil hê vir my kind ook…"

"It bothers me yes, I don't want to be looked at with such attention, because I accept that I have it but I don't think about it…I wish others should also treat me as any other person is treated. I don't

want them to look at me with that attention or to pity me. Um yes, I would like them to love me because love is the thing I miss most in my life and then that's what I want for my child as well...".

Hester says:

"Mense verwyt, um gee vir ons verwyte, hulle skel vir my gewoonlik ek het nie TB nie, ek het VIGS en sommige tye dan maak dit my seer man. Sommige tye dan voel ek net ek moet eenkant sit en net met iemand gesels wat vir my kan bystane"

"People blame, um give us reproaches, they usually scold me that I don't have TB, I have AIDS and sometimes it hurts me man. Sometimes I just feel I must sit apart and just talk to somebody who can support me".

The primary reason for wanting social support given by the women participants in the study conducted by Hackl et al. (1997), was to have an environment in which they could openly share their fears and feelings with people who were experiencing the same type of isolation and despair. According to Gillman and Newman (1996), keeping the disease a secret precludes possible sources of support and acceptance. Hackl et al. (1997) further state that non-disclosure may hinder a woman's ability to develop effective coping strategies and leave her vulnerable to fear, anger and depression. The obvious disadvantages of self-isolation and non-disclosure are that the person simultaneously lessens any possibility of receiving emotional support or understanding from family, friends and the community. While such self-imposed isolation protects the person from adverse reactions, it also excludes supportive responses and can, therefore, contribute to further psychological distress such as prolonged or intensified experiences of loneliness and depression (Kelly & Lawrence, 1988; Sandstrom, 1993)

5. PSYCHOSOCIAL NEEDS: ACCEPTANCE, SUPPORT AND EDUCATION

Research studies emphasise the importance of social support for psychological functioning and coping among persons with chronic illnesses. Support received from confidants and friends was observed to ameliorate the negative impact of physical illness on mental health. Studies focusing on the relationship between social support, hopelessness and depression found that for persons with AIDS, the more available social support was perceived to be, the less hopelessness and depression were reported (Zich & Temoshok, 1990).

Sewpaul and Mahlalela (1998) found in their study that living with the secret of an HIV diagnosis produces a great deal of pain and guilt and after disclosure, family support provides immense relief for women. According to Leask, Elford, Bor, Miller and Johnson (1997) the disclosure of one's status to close family or friends opens up the opportunity to receive social support. Research has shown that people with HIV infection who are integrated into social networks have higher levels of psychological well-being than those who are not (Siegel, et al., 1997). There is sufficient evidence that one's mood correlates with satisfaction with, or perceived availability of, social support, and that those satisfied with social support experience fewer depressive symptoms and have a greater ability to cope (Leask et al., 1997; Siegel et al., 1997). According to Land (1994), social support programmes should be designed to decrease isolation, self-blame and guilt. Psychosocial services and programmes planned to address women's needs for attachment and connection, for example, support groups and child care for HIV-positive women, might provide infected mothers with opportunities to talk about the burdens of secrecy and the complications of disclosure, and lessen the profound isolation and shame that are endemic to living with HIV and AIDS (Faithfull, 1997).

Writers emphasize that the absence of family members or friends can be filled by the presence and support of a confidant, for instance a therapist, health worker, or

a social support group. This can create the social conditions favourable to the achievement of the patient's social validation needs and prevent complete interpersonal estrangement, which can lead to loneliness and impaired mental health (Peplau & Perlman, 1982). Therefore therapy that focuses on issues of psychological adjustment, isolation and support, may benefit particularly women who fear disclosing their HIV status to friends or family. Given the multitude of issues confronting women with HIV/AIDS, perhaps the most important function of the therapeutic relationship is providing a reliable, safe, and supportive environment in which they can share their feelings and work through their concerns without fear of overburdening the other person (Jue, 1994). According to Van Kaams (quoted in Stuewe-Portnoff, 1988), the feeling of being really understood reduces loneliness, since "when you deeply understand me, that is co-experience what I experience, then you share my world" (p. 552). Therefore by serving as empathic listeners, therapists can help women express their pain and thus promote healing. This stress-buffering relationship and its beneficial role have also been noted in a qualitative study conducted by Poku and Linn (quoted in Linn, Poku, Cain, Holzapfel & Crawford, 1995) on African Americans living with HIV/AIDS.

Daniolos (1994) emphasises the important function of psychotherapy groups, especially when individual therapy is too costly. The type of group that he describes is unusual in bridging the gap between psychotherapy and support groups, exemplified in the working through of painful thoughts and feelings utilizing transferential and relational components in a support group setting.

It is thus clear that psychosocial support, either in a group or one-to-one setting, plays an important role in coping with life-threatening illnesses such as AIDS. Self-disclosure can often secure emotional support from others and promote adaptive coping. In fact, women have identified receiving psychosocial support as the single most helpful resource with all stages of HIV infection (Kelly & Lawrence, 1988).

Research studies in addition indicate that people living with HIV/AIDS attribute their survival to receiving good medical care and being equal partners in their care. Other reasons given for survival include a positive attitude, a healthy lifestyle, taking responsibility for oneself, prayer, meditation and spirituality (Pequegnat & Stover, 1999).

As discussed above, disclosure and social support are essential factors in addressing experiences of loneliness and preventing the development of severe psychological distress. Stigmatisation and its devastating consequences can drastically hinder this process. Zlotnik (1997) recommends community education as a means of breaking down the stigmatic response to those affected by the disease. According to Zlotnik (1997), it is important to examine and adjust people's individual values and the values of society so that people can respond in supportive ways, and the stigma associated with AIDS can be removed. Dukes and Denny (1995) suggest that HIV/AIDS education should continue to emphasise the infectious nature of the illness so that individuals will not perceive risk in casual contact with persons who are ill. According to them the downside to this strategy is that by emphasizing the infectious nature of the illness, most probably blame and derogation of those who are ill will continue. They recommend a continued strategy that advocates protection against HIV/AIDS; however, the programme must not overstate the risks because overstatement can trigger hysteria and increase prejudice.

According to Dukes and Denny (1995), the severity of suffering is also an issue. Popular discourse emphasises the exhaustion that is common when the person living with the illness is close to death, and it ignores the long middle phase during which the person may continue to function well. Dukes and Denny (1995) recommend that education must be aimed at presenting the course of the illness accurately (and not pejoratively), so that prejudice will not be magnified. According to Van Dyk (1994), the purpose of AIDS education / information programmes should be to offer practical advice about AIDS, to eliminate myths about the spread of HIV, to

correct faulty attributions about the causes of AIDS, to change attitudes, and most important, to establish a sense of compassion for infected people.

Hackl et al. (1997) emphasise that women and mothers have specific HIV/AIDS information needs regarding physiological, medical, gynaecological, psychosocial and childcare concerns. Most women interviewed by these researchers believed that an HIV diagnosis meant that they had AIDS and would die within a year or two. This lead to thoughts of suicide, anxiety and a depressed mood that were intensified by feelings of loneliness. For these participants, as well as for the partcipants in the present study, accurate and useful information regarding the above issues can lessen psychological distress and promote better functioning and improve coping skills.

Based on the present research findings strategies should be aimed at: 1) assisting women to obtain more support from friends, family members as well as health workers and professionals (inter alia individual or group therapy); 2) providing information to communities to stimulate and enhance understanding, acceptance and support for women with HIV/AIDS.

6. CONCLUSION

The widespread prevalence of loneliness among women living with HIV/AIDS and its negative psychosocial consequences has been well documented in the literature. The responses of the participants in the present study support these findings. The two main types of loneliness that these women experience are loneliness of emotional isolation and loneliness of social isolation. These terms can be defined as the absence of a close emotional attachment and lack of support and understanding of intimate others (emotional isolation) and the absence of an accessible and engaging social network and lack of social support and acceptance (social isolation). The most significant causes of loneliness for the participants in the present study are

stigmatisation; fear and/or shame of rejection and victimisation of self and family; fear of losing custody or care of their children; fear of losing financial and emotional support; and using secrecy and non-disclosure as main coping strategy for their emotional and physical safety. Experiences of emotional isolation are also provoked or enhanced by the lack of involvement and support from their partners and the partners' denial of the illness and its consequences. Experiences of social isolation are also caused or increased by the general lack of HIV/AIDS information, education and support services. Significantly, it is found that for most of the women the psychological effect of loneliness is primarily a depressed mood, accompanying feelings of hopelessness and helplessness and consequently further withdrawal from important others.

In general the same type of research as the present study is needed to detect and observe women and mothers living with HIV/AIDS who are experiencing loneliness in different communities. This is especially important considering that these women usually do not communicate to others what they are experiencing. Research such as the present study, allows for better narration and understanding of the subjective and specific experiences of women and mothers living with HIV/AIDS. This information can be used by health workers to assist the women to employ the available coping strategies prior to the emergence of the negative side effects that are attributed to loneliness. Loneliness often exacerbates women's emotional devastation; therefore understanding, acceptance and support could also prevent loneliness from becoming a chronic condition.

As stated in the previous section, strategies to address loneliness among low-income mothers living with HIV/AIDS need to be based on a two-pronged approach: focusing on the individual needs of the mothers as well as on the capacity of their communities to contribute to the fulfilment of these needs. Possible actions and solutions to meet the individual needs, to be listened to and heard as well as to be understood and accepted, could include: individual and group counselling/therapy;

family counselling; information and practical advice on women's issues, AIDS and effective coping strategies. Actions to enhance the capacity of the community to respond to these needs and provide support could be the following: improved social support services/programmes, e.g. support groups and child care; community education to reduce stigma and dispel myths, change negative attitudes and promote compassion and acceptance.

What this paper highlights is that psychosocial programmes and services in South Africa focusing on HIV-infected women should be based on information that incorporates research outcomes about HIV-infected women and mothers, their concerns, problems, needs and their use and lack of support, as well as their daily coping mechanisms. Targeting community-based, family-oriented, culturally sensitive psychosocial health care to women with HIV/AIDS can enhance and strengthen their psychological functioning and decrease loneliness, and thereby improve their overall quality of life.

Although the present paper focused on the participants' experiences of loneliness and its consequences, various positive coping mechanisms, such as acceptance, understanding, faith and religion, as well as negative coping mechanisms, such as alcohol abuse, were revealed by the participants. Comparing the effect and consequences of the various coping mechanisms of the participants can bring forth valuable information and guidelines for health workers supporting women with HIV and AIDS in general. The full results of this study, including the effectiveness of the participants' coping strategies, will be written up in a subsequent research paper entitled, "The Psychological Concerns of HIV-infected Low-income Mothers in the Winelands Region".

The present study has shortcomings that future researchers may ameliorate. For instance, loneliness is probably experienced differently in various cultures. According to Rokach (1999), loneliness is expressive of an individual's relationship

with his or her community. It is possible that cultural differences and the variety of ways in which people's social relations are organised will result in cross-cultural variations in the way people experience and cope with loneliness. Sibanda and Wilson (quoted in Rokach, 1999) state that little cross-cultural research on loneliness exists and emphasize the importance of performing such research. The homogeneous sample of the present study excluded examining and comparing the experiences of loneliness and the relationship between loneliness and its perceived causes and consequences between women and men with HIV/AIDS, different ethnic groups and people with different demographic characteristics such as socioeconomic level. Further research in South Africa should be conducted in these areas, which may aid in understanding loneliness among people living with HIV/AIDS and in recommending the most suitable ways of coping with it and lessening the psychological pain and distress it causes.

See Addendum E (p. 85): Summary of HIV-infected mothers' experience of loneliness, for the present study.

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Addendum A

VORM VIR OORWOë TOESTEMMING

Beste Deelnemer

Hiermee wil die navorser, Elsa de Villiers, u graag versoek om deel te neem aan 'n navorsingstudie wat ondersoek instel na die psigologiese besorgdhede, probleme en behoeftes wat vroue wat HIV + is, ervaar. Indien u bereid is om aan hierdie studie deel te neem, sal die navorser graag 'n onderhoud met u wil voer. Die onderhoud sal ongeveer drie uur duur en sal plaasvind in 'n privaat plek en op 'n tyd wat vir u geskik is. Die onderhoud sal op band opgeneem word.

Tydens die onderhoud sal vrae gestel word oor probleme en behoeftes wat u tans ondervind, asook hoe u daagliks funksioneer en lewe. Sommige van die vrae wat gestel word, sal egter persoonlik wees en kan onaangename herinneringe of gevoelens meebring. U moet asseblief kennis neem dat u die onderhoud te eniger tyd kan beëindig en dat u tydens die onderhoud kan weier om spesifieke vrae te beantwoord. Indien u van die studie onttrek, kan u vra dat al die data wat oor u versamel is, dit sluit die bandopnames en die transkripsies van die bande in, vernietig word. So 'n versoek sal deur die navorser uit gevoer word.

Om die vertroulikheid van die navorsingsmateriaal te verseker, sal geen name op die onderhoude of vraelyste geplaas word nie. Elke deelnemer sal gevra word om 'n kodenaam te kies, en daar sal 'n lys saamgestel word om aan te toon watter deelnemer met watter kodenaam ooreenstem. Slegs die navorser en haar studieleier sal tot enige van die data toegang hê, wat die lys met kodename, die bande en die transkripsies insluit. Die lys met kodename, bande en transkripsies sal in 'n toegesluite kas in 'n kantoor by die Stellenbosch Hospice gebêre word.

Alle inligting sal dus vertroulik hanteer word. Verslae oor die studie, dit sluit artikels in, sal nie enige ware name noem nie. Beskrywings van alle persone sal verbloem word sodat hulle nie herkenbaar sal wees vir enigiemand anders wat die studie lees nie. Daarom sal geen stuk inligting wat deur die studie versamel is op enige manier met enige spesifieke persoon of familie verbind kan word nie. Die bande waarop die onderhoude geneem word en die lys wat die name en kodename bevat, sal ook na die voltooiing van hierdie studie vernietig word.

Indien u vind dat vrae wat tydens die navorsingsonderhoud gestel word, pynlike of onaangename herinneringe of gevoelens oproep, en u sou met iemand hieroor wil praat, kan die navorser u verwys na 'n persoon of organsisasie wat u kan help. Verder vertrou die navorser dat die onderhoud interessant en nuttig sal wees vir elkeen wat aan die studie deelneem.

Indien u daarin belangstel om aan hierdie studie deel te neem, lees asseblief die volgende verklaring en teken hieronder.

Ek begryp dat deelname aan hierdie studie vrywillig is, en is bewus van die moontlike risiko's, voordele en ongerief verbonde aan my deelname. Ek aanvaar dat ek vrylik vrae kan vra, kan weier om vrae te beantwoord, en dat ek 'n sessie te eniger tyd kan beëindig. Ek begryp ook dat indien ek enige vrae of probleme het wat hierdie navorsing betref, ek die studieleier van hierdie navorsingsprojek, Dr Lou-Marie Kruger by 808 3460, kan kontak.

Handtekening van deelnemer **Datum**

Addendum B1

Interview Schedule

A. Socio-demographic items

1. Age: _____
2. First language: _____
3. Marital status / relationship status

- Married _____
- Live in lover _____
- Separated _____
- Divorced _____
- Widowed _____
- Never married _____

4. Education:

- Primary School Std: ___
- Secondary School Std: ___
- Tertiary education Qualification: _____

5. Do you work for an income?

....If yes,

- What type of work: _____
- Hours per day: _____

4. Monthly household income: R _____
5. Number of children: _____
6. Age of children:

- 0 - 5 years number: ____
- 6 - 12 years number: ____
- 13 - 18 years number: ____
- Older than 18 years number: ____

B. Health related items

1. HIV status of children:

- How many HIV positive: ___
- How many HIV negative: ___

2. Time since HIV diagnosis (of mother) in months: ___

3. Diagnostic categories:

- Asymptomatic: ___
- Symptomatic: ____
- AIDS: _____

4. HIV risk categories:

- Heterosexual sex: _____
- Rape: _____
- Drug use only: ____
- Transfusion: _____
- Unknown: _____

C. Psychosocial items

1. Emotional response:

   How did you feel after hearing that you were HIV positive?

   What did you think after learning that you were HIV positive?

   What did you do after hearing that you were HIV positive?

2. Disclosure:

   Have you discussed your diagnosis with anyone?

   Who was the first person you told and why?

   What has been the response of the people you've told?

   Have you told your children?

3. Intimacy and support:

   Do you have a intimate relationship right now?

   In what ways does this person give you support?

How do you feel about the support / lack of support you receive from him / her?

**Since you and your partner are both positive, how often do you discuss your status?

4. Affect and coping:

Could you describe a average day since you learned of your HIV status?

How are you dealing / coping with the diagnosis on a daily basis?

What is the hardest part of having HIV?

What helps you most in dealing / coping with HIV?

5. Future concerns and plans:

What is your biggest concern?

What are you most afraid of?

What do you hope for?

What do you feel might help you cope more effectively?

Where does HIV rank in the order of other things you have to deal with in your life?

What are your expectations now?

**If applicable

Addendum B2

Onderhoudskedule

A. Sosiodemografiese items

1. Ouderdom: _____
2. Huistaal: _____
3. Huwelikstatus / verhoudingstatus
   - Getroud ___
   - Woon saam met liefdesmaat ___
   - Woon apart van gade ___
   - Geskei ___
   - Weduwee ___
   - Nooit getroud nie ___
4. Opvoeding:
   - Laerskool St: _____
   - Hoërskool St:_____
   - Tersiêre opvoeding Kwalifikasie: _____
5. Doen u werk vir 'n inkomste? ____

   Indien ja,
   - Watter tipe werk: _____
   - Ure per dag: _____
6. Maandelikse huishoudelike inkomste: R _____
7. Getal kinders: _____
8. Ouderdom van kinders:

   0 - 5 jaar getal: ___

   6 - 12 jaar getal: ___

   13 - 18 jaar getal: ___

   Ouer as 18 jaar getal: ___

B. Gesondheidsverwante items

1. HIV-status van kinders:
    - Hoeveel HIV-positief: ___
    - Hoeveel HIV-negatief: ___
2. Tydsverloop sedert HIV-diagnose (van moeder) in maande: ___
3. Diagnostiese kategorieë:
    - Asimptomaties ___
    - Simptomaties ____
    - VIGS _____
4. HIV-risikokategorieë:
    - Heteroseksuele seks ___
    - Verkragting _____
    - Slegs dwelmgebruik ____
    - Oortapping _____
    - Onbekend _____

C. Psigososiale items

1. Emosionele reaksie:
    - Hoe het jy gevoel nadat jy gehoor het jy is HIV-positief?
    - Wat het jy gedink nadat jy uitgevind het jy is HIV-positief?
    - Wat het jy gedoen nadat jy gehoor het jy is HIV-positief?
2. Openbaarmaking:
    - Het jy jou diagnose met enigiemand bespreek?
    - Wie was die eerste persoon wat jy vertel het en hoekom?
    - Wat was die reaksie van die mense wat jy vertel het?
    - Het jy jou kinders vertel?
3. Intimiteit en ondersteuning:
    - Het jy op die oomblik 'n intieme verhouding?

- Op watter maniere gee hierdie persoon jou ondersteuning?
- Hoe voel jy oor die ondersteuning / gebrek aan ondersteuning wat jy van hom/ haar ontvang?
- ** Aangesien jy en jou metgesel albei positief is, hoe dikwels bespreek julle julle status?

4. Affek en hantering:
    - Kan jy 'n gemiddelde dag beskryf sedert jy uitgevind het van jou HIV-status?
    - Hoe hanteer jy die diagnose op 'n daaglikse basis?
    - Wat is die moeilikste daarvan om HIV te hê?
    - Wat help jou die meeste met jou hantering van HIV?
5. Toekomskwellinge en -planne:
    - Wat is jou grootste kwelling?
    - Waarvoor is jy die bangste?
    - Waarvoor hoop jy?
    - Wat voel jy kan jou dalk help om dinge meer effektief te hanteer ?
    - Waar staan HIV in volgorde van belangrikheid op die lys van ander dinge wat
    - jy in jou lewe moet hanteer?
    - Wat is jou verwagtinge nou?

** Indien van toepassing

Addendum C1

Revised UCLA Loneliness Scale (RULS)

Participants will be read the following statement: "Indicate how often you have felt the way described in each statement using the following scale".

4 = I have felt this way often

3 = I have felt this way sometimes

2 = I have felt this way rarely

1 = I have never felt this way

1. I feel in tune with the people around me.
2. I lack companionship.
3. There is no one I can turn to.
4. I do not feel alone.
5. I feel part of a group of friends.
6. I have a lot in common with the people around me.
7. I am no longer close to anyone.
8. My interests and ideas are not shared by those around me.
9. I am an outgoing person.
10. There are people I feel close to.
11. I feel left out.
12. My social relationships are superficial.
13. No one really knows me well.
14. I feel isolated from others.
15. I can find companionship when I want it.
16. There are people who really understand me.
17. I am unhappy being so withdrawn.
18. People are around me but not with me.
19. There are people I can talk to.
20. There people I can turn to.

Addendum C2

"Hersiene UCLA-eensaamheidskaal"

Die volgende stelling sal aan deelnemers voorgelees word: "Dui aan hoe dikwels jy voel soos wat in elke stelling beskryf word, deur die volgende skaal te gebruik."

4 = Ek voel dikwels so
3 = Ek voels soms so
2 = Ek voel selde so
1 = Ek het nog nooit so gevoel nie

1. Ek voel in harmonie met die mense rondom my. ___
2. Ek het nie geselskap nie. ___
3. Daar is niemand na wie ek my kan wend nie. ___
4. Ek voel nie alleen nie. ___
5. Ek voel deel van 'n groep vriende. ___
6. Ek het baie in gemeen met die mense rondom my. ___
7. Ek is nie meer naby aan enigiemand nie. ___
8. My belange en idees word nie gedeel deur die mense rondom my nie. ___
9. Ek is 'n persoon wat na buite lewe. ___
10. Daar is mense aan wie ek naby voel. ___
11. Ek voel uitgelaat. ___
12. My sosiale verhoudings is oppervlakkig. ___
13. Niemand ken my regtig goed nie. ___
14. Ek voel afgesonder van ander mense. ___
15. Ek kan geselskap kry wanneer ek dit wil hê. ___
16. Daar is mense wat my regtig verstaan. ___
17. Ek voel ongelukkig omdat ek so teruggetrokke is. ___
18. Mense is rondom my maar nie by my nie. ___
19. Daar is mense met wie ek kan praat. ___
20. Daar is mense na wie ek my kan wend. ___

To make the RULS more user-friendly a visual scale as below was shown to the participants

4	3	2	1
Ek voel dikwels so	**Ek voel soms so**	**Ek voel selde so**	**Ek het nog nooit so gevoel nie**

Addendum D

List of general themes:

1. Fear of disclosure / shame (Vrees vir bekendmaking / skaamte)
2. Stigmatisation (Stigmatisering)
3. Guilt feelings because of infecting others (Skuld gevoelens oor infektering van ander)
4. Fear of infecting others (Vrees dat sy ander sal infekteeer)
5. Feelngs of blame / anger towards the person responsible for infecting her (Verwyte en woede teenoor persoon wat haar geïnfekteer het)
6. Concerns regarding physical deterioration / disease symptoms (Bekommernis oor fisiese agteruitgaan / siekte simptome)
7. Personal losses / changes (physical and psychological) (Persoonlike verliese / veranderinge)
8. Concerns / fears regarding death and dying (Bekommernis / vrese vir die dood / lyding)
9. Suicidal thoughts / thoughts on death as a means of being rescued / set free (Selfmoord gedagtes / gedagtes aan dood as bevryding)
10. Uncertainty regarding duration of life / recovery / the future (Onsekerheid oor lewensduur / genesing / toekoms)
11. Concerns / needs regarding faith and prayer / participating in church activities (Bekommernis oor / behoefte aan geloof-gebed / kerk aktiwiteite)
12. Concerns regarding children (Bekommernis oor kinders)
13. Concerns regarding her partner's illness (Bekommernis oor man / mansvriend se siekte toestand)
14. Lack of / need for support and acceptance (Tekort / behoefte aan ondersteuning / ontferming / aanvaarding)
15. Effect of HIV/AIDS on daily functioning (Effek van HIV/VIGS op daaglikse funksionering)

16. Loneliness / isolation (Eensaamheid / isolasie)
17. Concerns regarding coping with the illness and consequences (Bekommernisse rondom die hantering van siekte toestand)
18. Alcohol abuse and consequences (Alkohol misbruik en gevolge)
19. Relationship problems (Verhoudings probleme)
20. Concerns regarding intimate / sexual relationship (Bekommernisses oor intieme / seksuele verhouding)
21. Financial problems and concerns (Finansiële probleme / bekommernisse)
22. Concerns regarding housing / living conditions (Bekommernis oor / behoefte aan huisvesting / fisiese lewensomstandighede)

Addendum E